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## DOCTOR OF PHILOSOPHY

### Facing the diagnosis of autism spectrum disorder (ASD) in Ireland and Romania: a family approach

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Queens University Belfast  
School of Education

Facing the diagnosis of autism spectrum disorder (ASD) in  
Ireland and Romania: A family approach.

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## Foreword

This thesis is dedicated to my good friend Dr. Eugen Goaga, who is unfortunately not with us anymore, for his support and a life dedicated to research.

The idea for this thesis started twelve years ago when I was an undergraduate student, who was interested in ASD, which was then a new and mysterious field of study. After many years, this idea has become a reality and hopefully, the outcome of this thesis is to could provide useful information to the understanding families of children with ASD.

I would like to thank my supervisor, Prof. Karola Dillenburger, for her great ideas, comments and encouragement.

Thanks and love must go to my husband Sorin for his encouragement and support.

Finally, many thanks to the Irish and Romanian families who worked with me, for their time and willingness to participate in this research. Their support is very much appreciated.

Cornelia Munteanu

## Abstract

To date there has been little research on family changes caused by having a child of 0 to 7 years old with autism in the family. This thesis examines the diagnosis of autism spectrum disorder (ASD) in the context of the family and compared families' experiences in Ireland and Romania. This research took a family system perspective, exploring how families with children on the autism spectrum function during the particularly stressful period of the diagnosis process and thereafter.

This Ph.D. thesis contains the results of a comparative study of Irish and Romanian families of children with ASD.

The analysis of the similarities and differences of how families who are raising a child with autism function during the diagnostic process is expected to provide a better understanding of the overall experience of families and to improve sensitivity during the diagnostic process.

Fifty-four families and their children were recruited from two institutions: 24 families from Ireland (Dublin, Cherry Orchard Hospital) and 30 families from Romania (Timisoara, Casa Faenza). The children were aged between 2 and 7 years. During the process of data collection, a relatively large number of Irish families refused to participate in this research, or accepted the invitation initially and then later refused it or stated that they are very 'busy'. A total number of 77 Irish families were contacted by the researcher and asked to participate in this study. Only 24 families agreed to participate and 53 refused to participate. In contrast, all of the 30 Romanian families who were contacted and asked to participate in this research accepted.

This comparative research study is unique as no previous studies have focused on the impact of ASD diagnostic on family systems across two cultures in Europe.

The results showed that families of a child with ASD in Ireland had different experiences during the diagnostic process of their child, compared to the Romanian

families. Differences were also found between the two groups with regard to the role of mother and father in raising a child with ASD, parents' worries when received the diagnosis, parents' awareness/knowledge about ASD, and parents' level of involvement. A semi-structured interview was used to analyse similarities and differences between the two groups. The duration of the diagnostic process was significantly different between the two countries.

Aspects of family functioning were tested using the family adaptability and cohesion evaluation scale IV (FACES IV) (Olson et al., 2010). The results showed similarities and differences between the two groups in terms of mean scores for family cohesion, flexibility, communication and satisfaction.

Present findings should be used by policymakers in improving parent's accessibility to ASD services for their children (diagnostic and post-diagnostic) in both countries. There is a crucial need to develop specialized services for children with ASD.

The findings indicate that both instruments used (semi structured interview and FACES IV) provided valuable information about family functioning and family experience during the diagnostic process. The limitations of the study were discussed.

*Keywords: children with ASD; diagnosis process; family systems; cross-cultural comparative study, Ireland and Romania*

## 1. Introduction

While the causes of autism spectrum disorder (ASD) still are not fully understood, increasingly research focuses on interventions and treatment of children diagnosed with ASD. Considerably less attention is paid to family systems, family functioning, and family needs.

Although autism is considered to be a worldwide disorder, little is known about the implications of diagnosis on family life in many countries, such as Ireland and Romania. The diagnosis of autism and its implications on family life in different countries and cultures has not been explored on a large-scale to date. The present comparative study may contribute to our understanding of autism from a family perspective.

This research study takes a family system perspective, exploring how families with children on the autism spectrum function during the particularly stressful period of the diagnosis process and thereafter. Recommendations made in this research relate to the need for more empirical studies that address in detail family systems, family needs, the assessment and diagnostic process, service provision, social support networks, and additional stressful life events.

This comparative study includes Irish families and Romanian families who have children on the autistic spectrum and contributes to family studies and autism research field with a specific focus on the diagnosis. Furthermore, the family aspects that are identified, form the basis of a family functioning/experience profile that can be used to help identify particularly vulnerable families and therefore enable professionals to respond early in order to support families holistically and effectively and to promote child-family-centered assessment and intervention (Dover and LeCouteur, 2007).

There are many similarities and differences between European countries. This study addressed issues related to families who experience autism spectrum disorder (ASD) in one or more of their children; in particular, the study sought to find out how



families function around the time of diagnosis. In order to set this study in a European context, two countries that exemplify the diversity of Europe (Ireland and Romania), were chosen for comparison. Both have experienced large-scale political, economic and social changes in recent years and both have been affected by the recent economic downturn.

The present study focused on the diagnosis of ASD in the context of the family and compares families experiences in Ireland and Romania. The main aim of the study is to provide an overview of the autism diagnostic within a cultural context.

The rationale of choosing these two countries was that the researcher is of Romanian origin (who currently lives and works in Dublin, Ireland) and has experience in working with children with ASD and their families in both countries.

Irish and Romanian families from both institutions, Casa Faenza Romania and Cherry Orchard Hospital Dublin, were a convenient sample, as the researcher has worked as an educational psychologist at Casa Faenza Romania and as a senior social work practitioner at Cherry Orchard Hospital, Dublin, Ireland. However, the relationship with the participants in this study was strictly for research purposes only.

Few studies have examined family functioning and experience during the diagnosis process, and none has offered a direct comparison of these issues between two countries. The main contribution of this research is to provide an insight into family systems variables, structural and functional characteristics of families during this process within a European comparative context.

In order to understand the two cultural contexts and the comparative nature of this study, Chapter 4 and Chapter 5 describes Irish and Romanian families from different perspectives: historical, demographic and family aspects, political/legislative, assessment/diagnosis and service provision.

Daly (2004) indicated that there are different definitions of family in Ireland that include: a cultural description, a political description, a constitutional description and a historical description. However, family life in Ireland is becoming more diverse in

terms of the variety of family types, as the nature of the family is changing. Currently in Ireland, there are more families from different ethnic and cultural backgrounds than in the past. Daly (2004) states that the idea of the family as predominantly nuclear (consisting of parents and children) is questionable. In terms of the involvement of extended family, Daly stated that “today’s parents rely very much on their own parents (for minding the children or for financial support) and on other relatives” (Daly, 2004, p. 23).

The Education for Persons with Special Educational Needs (EPSEN) Act (Government, Ireland, 2004) provides the legislative framework for the delivery of education for children with disabilities between 4 and 18 years of age.

In Ireland, the Disability Act 2005 stipulates that children under 5 years of age have a right to an independent assessment of their health and educational needs. After assessment, families will receive an assessment of need report specifying their child’s health and educational needs and services required to meet those needs. The Disability Act, 2005 is largely described in Chapter 5.

The medical system in Ireland (Health Service Executive – HSE) provides public health services in all of the hospitals and communities. The main constraint in the Irish medical system are the long waiting lists to gain access services. This difficulty is largely discussed and analysed in present study and was emphasized by parents.

As specified in Chapter 4, Romania has faced a crisis concerning childcare, especially with regard to abuse and neglect in institutional care of the most vulnerable children, especially during the communist era. The communist legacy is still felt by parents’ perception of life in Romania. For example, during the communism era, Romanian people were deprived of information, services, food and free speech. Ireland did not experience such disadvantages. Post-communist Romanian families (after 1989) had no support from other people and public services and had to do everything for their child.

Family life in Romania is similar in some ways to Irish family life, but has a few differences. Family life in Romania, similar to Irish family life, is becoming more

diverse in terms of the variety of family types. Romania did not experience immigration on such a large-scale as Ireland has. Ireland experienced a wave of immigration only in the last 10 years when people from the Eastern European countries, Asia and Africa came to live and work here. In terms of the involvement of the extended family, similar to Ireland, Romanian parents rely on their parents to look after their children.

The Minister of Education in Romania is responsible for providing educational services for all children. The main purpose of the Minister of Education (Ministerul Educatiei) is to coordinate and monitor the national educational system in Romania.

The first school for children with autism in Romania (preschool and elementary education) was inaugurated in 2013 in Cluj-Napoca. In other areas, children with ASD attend special schools for children with disabilities or mainstream schools. The legislation regarding the right of people with autism, Law no 151 from 12.07.2010, provides health and special education for people with autism. Chapter 4 underlines the most important aspects about services for people with autism in Romania.

Non - governmental centers for children with autism in different parts of the country in Romania offer services for children and their families (e.g. Casa Faenza in Timisoara, Autism Transilvania in Cluj-Napoca, Nagual in Slatina, etc.).

The Romanian Health Ministry initiated a project and developed the Screening Questionnaire for Autism Spectrum Disorders (Chestionarul de Screening pentru Tulburări de Spectru Autist – CS-TSA), designed to be used by the Romanian GPs. This instrument is an early screening for ASD symptoms. David et al. (2013) specified that the CS-TSA has been developed based on the model provided by the Checklist for Autism in Toddlers (Baron-Cohen, Allen, & Gillberg, 1992). In their study, David et al. (2013), described the initial validation study of the newly developed screening instrument CS-TSA. The results support the CS-TSA fidelity, validity and clinical utility as a screening instrument.

The Minister of Health (Ministerul Sanatatii) is the equivalent of the Health Service Executive in Ireland. The main difference is that, Romanian parents have to pay extra

money to the doctors in order to access their services. In other words, parents have to bribe them. The medical and educational systems in Romania and all public services are similar in terms of inequity and corruption.

Both the medical system and the educational system in Romania need a fundamental change. However, people can always choose private healthcare or education, if they can afford it.

A young Romanian doctor called Claudia Radu who chose to leave Romania in 2004 and work as a doctor in London stated that:

Bribery in Romania is everywhere – you can't escape it. But in the healthcare system it's at its worst. The tradition of gift-giving in Romania goes back a long way and it has always been the custom to give some money, food or drink as a thank you for good service.

(The Guardian, 2008).

There is a fine line between the tradition of giving some money for services and bribery in Romania. Is this a part of a cultural heritage or it is more than that?

The *objectives* of this research were:

To explore the experience of diagnosis of ASD from the perspective of parents; and to compare the experience of diagnosis in two European cultures (Ireland and Romania);

To determine family functioning, i.e. family communication, cohesion, flexibility, satisfaction in families with children recently diagnosed with ASD; and to compare functioning in recently diagnosed families in two European cultures (Ireland and Romania)

To explore accessibility to treatment/service options for families whose child(ren) have recently been diagnosed with ASD; and to compare treatment/service options in two European cultures (Ireland and Romania)

The term *family functioning* in this study includes questions about how families adapt, the cohesion and flexibility of the family, family communication, the relationship between family subsystems, the family structure and allocation of family roles that were assessed with family adaptability and cohesion evaluation scale IV (FACES IV) and a semi-structured interview, and treatment options available to children and their families. Particular emphasis was put on a ‘sub-system function’ of parental and sibling subsystems and on extended family subsystems.

*The main research questions were:*

- Are there any differences and/or similarities between aspects of family functioning in Irish and Romanian families of children with ASD during the diagnosis process?
- What is the experience of parents during the diagnostic process of their child/ren in Ireland and Romania?
- What is the parents view in accessing diagnostic and post-diagnostic services for their children in Ireland and in Romania?
- Is the age of child’s diagnosis and duration of diagnosis in Ireland different to that in Romania?

*Hypotheses and null hypotheses were:*

1. Aspects of family functioning (cohesion, flexibility, communication and satisfaction) in Irish families are different to aspects of family functioning in Romanian families

*There is no difference between aspects of family functioning in Romanian and Irish families.*

2. Main family worries regarding their child when received a diagnosis in Ireland are different than family worries regarding their child when received diagnosis in Romania.

*There is no difference between Romanian and Irish families in terms of family worries.*

3. Irish families show a level of involvement in their child's development different to that of Romanian families.

*There is no difference between Romanian and Irish families regarding level of involvement in their child's development.*

4. Irish families have a different perspective about the role of mother/father in raising a child with ASD than do Romanian families.

*There is no difference between Romanian and Irish families regarding the role of mother/father in raising a child with ASD*

5. The experience of a family regarding their child when they received diagnosis in Ireland is different to the experience of a family regarding their child when they received a diagnosis in Romania.

*There is no difference between Romanian and Irish families in terms of family experience.*

6. The age of children at diagnosis with ASD and the duration of diagnosis in Ireland is different to the age of children at diagnosis with ASD and the duration of diagnosis in Romania.

*There is no difference between Romanian and Irish children in terms of age of diagnosis with ASD.*

### 1.1. The history of autism

In 1911, Swiss psychiatrist Eugen Bleuler first introduced the concept of autism to describe the symptomatology of schizophrenic patients. Bleuler did not use the term autism in connection with children, he used to describe the autistic thinking of schizophrenic adults (Bender, 1955). However, it was only in 1971 that the term autism was distinguished from schizophrenia (Kolvin, 1971).

Similarities and differences between autism and schizophrenia have been discussed in the literature since the first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1952. However, at the present time, schizophrenia is considered a diagnosis distinct from autism although a dual diagnosis is identified in some cases (DSM – IV-TR, 1994).

In DSM-IV, pervasive developmental disorders (PDD) were a broad category that includes: 299.00 Autistic Disorder, 299.80 Rett's Disorder, 299.10 Childhood Disintegrative Disorder, 299.80 Asperger's Disorder, and 299.80 Pervasive Developmental Disorder Not Otherwise Specified.

In ICD-10, pervasive developmental disorders are a broad category that include: F84.0 Childhood autism, F84.1 Atypical autism, F84.2 Rett's syndrome, F84.3 Other childhood disintegrative disorder, F84.4 Overactive disorder associated with mental retardation and stereotyped movements, F84.5 Asperger's syndrome, F84.8 Other pervasive developmental disorders, and F84.9 Pervasive developmental disorder, unspecified.

The term "autism" comes from the Greek word *autos*, meaning *self*, and was used first in a clinical setting by the Austrian psychiatrist Leo Kanner (1943). He used the term "early infantile autism" for 11 children (8 boys and 3 girls) between the ages 2 and 8 years whose condition was characterised by social deficits, deviant quality of communication, and restricted and repetitive interests and behaviours (Rutter et al., 1994; ICD-10, 1998; DSM-IV, 1994).

One year later, an Austrian Paediatrician, Hans Asperger (1944) described children with “autistic psychopathology” as having qualitative impairment in social interaction; restrictive, repetitive and stereotype patterns of behaviour, interests and activities; clinically significant impairment in social, occupational, or other important areas of functioning. These children had no clinically significant general delay in language and cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour and curiosity about the environment in childhood (DSM-IV 299.80, 1994). Evidently, both Kanner and Asperger described children with autism as having difficulties in communication, social interaction and behaviour.

Andreas Rett was an Austrian neurologist (1924-1997) who described 22 girls who present a normal functioning and psychomotor development after birth and during the first 5 months, and a normal prenatal and perinatal period. At 5 months, there was a regression of previously acquired skills occurred, head growth decelerated, a loss of some fine motor skills and stereotypical hand movements developed, interest in social environment diminished, and problems with the coordination of gait and trunk movements appeared, as well as severe impairments in expressive and receptive language and severe psychomotor delay (DSM-IV 299.80, 1994).

A wide body of literature has accumulated since about the diagnosis and science-based intervention for children with autism and their families. The Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was released in May 2013. This edition includes only autism spectrum disorder (299.00) under the neurodevelopmental disorders section. PDD was replaced by autism spectrum disorder (ASD); the term Asperger Syndrome is no longer used in DSM5 and instead ASD is defined along three levels of severity: Level 1 – requiring support; Level 2 – requiring substantial support; Level 3 – requiring very substantial support.

However, since the fieldwork reported in this thesis was conducted prior to the publication of DSM5, for the context of this thesis, the DSM-IV definitions are used throughout.

The term autism spectrum disorder (ASD) is used to illustrate the pervasive and varied features of these developmental disorders. ASD is described in both the



Diagnostic and Statistical Manual of Mental Disorders-4th Edition (DSM-IV, 1994) and the International Classification of Diseases-10th Revision (ICD-10, 1998) as characterised by abnormalities in: social interactions, communication and stereotyped interests and activities. However, there are some differences in the categorisation between the two manuals.

While the DSM-IV (1994) definition of ASD included childhood disintegrative disorder; Rett's disorder; autistic disorder; pervasive developmental disorder-not otherwise specified; and Asperger disorder, the ICD-10 (1998) classification includes pervasive developmental disorders; childhood autism; atypical autism; Rett's syndrome; other childhood disintegrative disorder; overactive disorder associated with mental retardation and stereotyped movements; Asperger's syndrome; other pervasive developmental disorders; and pervasive developmental disorder, unspecified. Definitions of ASD were explored during the history. The next chapter outlines the concept and definition of ASD.

## 1.2. Definition of autism spectrum disorder (ASD)

The term autism spectrum disorder (ASD) is described in the Diagnostic and Statistical Manual of Mental Disorders (DSM; used in the USA and internationally) and the current International Classification of Diseases (ICD, used mainly across Europe) as characterized by abnormalities in social interactions, communication and stereotyped interests and activities. Manifestations of these three categories of difficulties were considered the main criteria for diagnosis.

The history of change in categorisation of this complex disorder continued in DSM5 (2013). The DSM5 includes only one category (autism spectrum disorders) and thus discontinues the use of subcategories in favour of a description of the dimensions and severity of symptoms.

The specifiers for severity are:

Social communication impairment (level 1, 2, 3)

Restricted interests/repetitive behaviours (level 1, 2, 3)

Level 1 – requiring support

Level 2 – requiring substantial support

Level 3 – requiring very substantial support

These levels describe deficits in social communication and restricted, repetitive behaviours. Thus, the three diagnostic domains from DSM-IV became two (social communication and restricted, repetitive behaviours). Rett's disorder and other subcategories are defined by using of a specifier: associated with known medical or genetic condition or environmental factor.

DSM5 brought a new approach to the ASD diagnosis and this could lead to a better understanding of ASD diagnosis and transparency, in order to avoid any diagnostic confusion. DSM5 excluded the term “pervasive developmental disorders”, as autistic symptoms are specific to two explicit domains and therefore are not viewed as pervasive.

It is important to recognize that there are some differences in the categorisation between the two diagnostic manuals. The DSM5 brought changes in

symptomatology. In DSM-IV, symptoms have to be apparent prior to the age of 3 years. The DSM5 specifies that the symptoms begin in early childhood, but symptoms may not be fully manifest until social demands exceed capacity (e.g. during middle-school years, later adolescence, or young adulthood).

The DSM5 (2013) ASD criteria include:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging for example, from abnormal social approach and failure of normal back and forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in non-verbal communicative behaviours used for social interaction, ranging for example, from poorly integrated verbal and non-verbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and non-verbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g. simple motor stereotypies, lining up toys or flipping plates, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or non-verbal behaviour (e.g. extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take the same route or eat the same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g. strong attachment to, or preoccupation with, unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability or global developmental delays. Intellectual disabilities and autism spectrum disorder frequently co-occur; to make co-morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

The DSM-IV (1994) definition of ASD included:

*Childhood disintegrative disorder* (299.10), characterized by apparently normal development for at least the first 2 years after birth and significant loss of previously acquired skills (before age 10 years), impairment in social interaction, communication, restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities, including motor stereotypies and mannerisms.

*Rett's disorder* (299.80), characterized by normal prenatal and perinatal development, normal psychomotor development through the first 5 months after birth, normal head circumference at birth, deceleration of head growth between ages 5 and 48 months, loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements, loss of social engagement, appearance of poorly coordinated gait or trunk movements, severely impaired expressive and receptive language development with severe psychomotor retardation. Rett's disorder has been reported only in females.

*Autistic disorder* (299.00), characterized by impairments in social interaction, communication, symbolic or imaginative play and restricted repetitive and stereotyped patterns of behaviour, interests, and activities prior to age 3 years.

*Pervasive developmental disorder-not otherwise specified (including atypical autism)* (299.80), characterized by severe and pervasive impairment in the development of reciprocal social interaction, verbal or non-verbal communication skills and the presence of stereotyped behaviour, interest and activities.

*Asperger disorder* (299.80), characterized by qualitative impairments in social interaction, restricted repetitive and stereotyped patterns of behaviour, interests, and activities, significant impairment in social, occupational, or other important areas of functioning, no significant general delay in language and cognitive development or in the development of age-appropriate, self-help skills, adaptive behaviour and curiosity about the environment in childhood.

The ICD-10 (1998) classification of pervasive developmental disorders (F 84) includes the following:

*Childhood autism* (F84.0), characterized by abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour.

*Atypical autism* (F84.1) differs from childhood autism in terms of either age of onset or failure to fulfil all three sets of diagnostic criteria.

*Rett's syndrome* (F84.2), characterized by apparently normal or near-normal early development, followed by partial or complete loss of acquired hand skills and of speech, together with deceleration in head growth, usually with an onset between 7 and 24 months of age. Social and play development are

arrested in the first 2 or 3 years, but social interest tends to be maintained. Reported only in girls.

*Other childhood disintegrative disorder* (F 84.3), characterized by a period of normal development before onset, and by a definite loss, over the course of a few months, of previously acquired skills in at least several areas of development, together with the onset of characteristic abnormalities of social, communicative, and behavioural functioning.

*Overactive disorder associated with mental retardation and stereotyped movements* (F 84.4), characterized by severe over activity, motor stereotypies, and moderate to severe mental retardation.

*Asperger's syndrome* (F 84.5) characterized by qualitative abnormalities of reciprocal social interaction, restricted, stereotyped, repetitive repertoire of interests and activities, no delay in language or in cognitive development.

*Other pervasive developmental disorders* (F 84.8); and

*Pervasive developmental disorder, unspecified* (F 84.9), a residual diagnostic category that should be used for disorders which fit the general description for pervasive developmental disorders.

As can be seen from the above, categorisation of ASD is difficult and inconsistent. To make matters worse, autism was described in all DSM editions under different labels. Thus, in order to understand the definitions of autism and terminology used, it is useful to have a brief overview of all DSM editions (DSM I, 1952; DSM II, 1968; DSM III, 1980; and DSM IV, 1994)

In order to understand the development of diagnostic criteria, it is important to look at the history of their development. The DSM I was released in 1952 and did not include autism as a specific diagnosis. Autism was classified under the schizophrenic reactions 000-x20, childhood type 000-x28 as “psychotic reactions in children, manifesting primarily autism” (DSM I, 1952, p. 28).

The second edition of The Diagnostic and Statistical Manual of Mental Disorders (DSM II) was released in 1968 and, similar to the first edition, autism was not included in it as a specific diagnosis. Autism appeared under 295.8 schizophrenia, childhood type in this edition:

This category is for cases in which schizophrenic symptoms appear before puberty. The condition may be manifested by autistic, atypical, and withdrawn behaviour; failure to develop identity separate from the mother's; and general unevenness, gross immaturity and inadequacy in development. These developmental defects may result in mental retardation.

(DSM II, 1968, p.35).

The diagnosis of autism was included for the first time in DSM III (1980) as a specific diagnosis under the category of pervasive developmental disorders: 299.0x infantile autism. The diagnostic criteria for infantile autism included six symptoms:

- onset before 30 months of age
- pervasive lack of responsiveness to other people (autism)
- gross deficits in language development
- if speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal
- bizarre responses to various aspects of the environment, e.g. resistance to change, peculiar interest in or attachments to animate or inanimate objects
- absence of delusions, hallucinations, loosening of associations and incoherence as shown in schizophrenia (p. 35).

Apart from 299.0x infantile autism, pervasive developmental disorder in DSM III included: 299.00 infantile autism, full syndrome present; 299.01 infantile autism, residual state; 299.9x childhood onset pervasive developmental disorder; 299.90 childhood onset pervasive developmental disorder, full syndrome present; 299.91 childhood onset pervasive developmental disorder, residual state; 299.8x atypical pervasive developmental disorder. As described above, the DSM IV and its text

revision DSM IV-TR kept some of these distinctions and included Asperger disorder as a separate category.

Another topic of intense debate is the term “lifelong” in many descriptions of ASD. The first suggestion to introduce autism as a spectrum and a lifelong disorder was introduced by Wing and Gould (1979). The development of effective, evidence-based early interventions has questioned the assumption that ASD is necessarily lifelong for all individuals diagnosed with ASD in early childhood (Dillenburger, 2011). Yet, many authors and professionals still considered it a lifelong condition, although increasingly, studies have proposed the removal of the assumption. Helt et al. (2008) considered that between 3% and 25% of children with ASD lose their diagnosis and enter in a normal range of cognitive, adaptive and social skills. Predictors of recovery include early diagnosis and treatment (i.e. behaviour analytic techniques), a diagnosis of pervasive developmental disorder-not otherwise specified, and high levels of baseline intelligence, motor and verbal skills.

In summary, since Kanner (1943) first introduced the term of early infantile autism, the terminology of autism has been inconsistent across time, influenced by theoretical assumptions at the time, e.g. Bettelheim’s (1967) assumption that autism was caused by lack of emotional bonding, i.e. “refrigerator mothers”. Lack of recognition as a separate diagnosis, e.g. it was grouped with “childhood schizophrenia” (Bender, 1956) and thought to be manifesting the earliest form of adult schizophrenia, or thought to be a basic cognitive deficit (Rutter, 1983). Today, individuals with ASD receive a dual diagnosis if they also have an intellectual disability (Hill, 2004). The work and research to synchronize both manuals DSM5 and ICD began in 2010 and is ongoing.



### 1.3. Characteristics of children with ASD

It is important to specify that individuals with autism spectrum disorder (ASD) exhibit a complex clinical picture that can create confusion for clinicians. Children with autism present difficulties in many areas of development, such as communication, behaviour, social interaction, specific interests, eating and sleeping, toilet training, sensory issues, motor skills, emotion recognition, etc. They may also present some associated problems (comorbidities or co-occurrences) such as ADHD (attention deficit and hyperactivity disorder) anxiety or epilepsy. The core deficits in children with ASD were described in the previous chapter. Other common difficulties that children with ASD have are: physical characteristics, eating pattern, sleep pattern, toilet training, sensory integration, motor skills and mental health co-morbidity.

*Physical characteristics:* Happe and Frith (1996) described autism as a “disorder without physical stigmata; indeed the normal or attractive appearance of children with autism stands in stark contrast to other forms of mental handicap” (p. 1380). However, recent research found minor physical anomalies (dysmorphology). Using photographs to identify dysmorphology, Angkustsiri et al. (2011) identified that significantly more children with ASD were classified as dysmorphic compared to typically developing children. Both microcephaly and macrocephaly are observed (DSM IV-TR, 2000).

*Eating pattern:* Many children with ASD have eating difficulties and mealtimes could be problematic for both children and family members. Nadon et al. (2011) completed an eating profile of children with ASD and their siblings. Their findings suggest that children with ASD have significantly more mealtime problems (a mean of 13.3) than their siblings (5.0 problems). They tend to present with more eating problems as infants than younger children. Mealtime problems are reported in 46–89% of children with autism spectrum disorders (ASD) (Ledford and Gast, 2006). Children with ASD may have difficulties in accepting new food and textures. They also refuse food and have particular mealtime routines.

*Sleep pattern:* The literature suggests that children with autism are affected by sleep difficulties. Hoffman et al. (2006) indicate that children with autism present bedtime resistance, sleep anxiety, parasomnias, sleep disordered breathing, daytime sleepiness, night walking, sleep onset delay and abnormal sleep duration. In their study, sleep problems were significantly higher in children with autism than in typically developing children.

Using a longitudinal study, Sivertsen et al. (2012) concluded that the prevalence of chronic insomnia was more than ten times higher in children with autism compared to the controls. The sleep problems were more persistent over time. They also concluded that emotional and behavioural problems explained the association between ASD and sleep problems.

*Toilet training:* Some children with ASD may experience difficulties in toilet training. Bainbridge et al., (1999) conducted research on the effects of priming in introducing toilet training to a boy with ASD using an ABAB design. The findings showed an increase in initiation of toilet used and a decrease in the number of wet diapers when priming was used.

LeBlanc et al., (2005) conducted a study on three children with ASD who were previously non-responsive to low-intensity toilet training interventions and were toilet trained using an intensive toilet-training procedure. The findings show that each child achieved continence, and two children eventually initiated the majority of toileting events based on a procedure developed by Azrin and Foxx (1971) for primary urinary incontinence.

*Sensory integration:* Schaaf et al., (2011) explored in their study how sensory-related behaviours of children with autism have affected family routines. Findings indicated that

sensory behaviours are one factor that limited family participation in work, family and leisure activities; and that parents employed specific strategies to manage individual and family routines in light of the child's sensory-related behaviours.

The literature shows that approximately 80% of individuals with ASD show behaviours related to poor sensory modulation (e.g. cover their ears for auditory stimulus; spinning) (Leekam et al., 2007; Rogers and Ozonoff, 2005; Rogers et al., 2003). Myles et al. (2004) showed that sensory processing difficulties influence social and emotional behaviours in children with ASD, especially children with Asperger syndrome.

*Motor skills:* In addition to the core deficits and other symptoms and difficulties, children with ASD may demonstrate motor difficulties. Qiu et al. (2010) demonstrated that differential disruption of parallel frontosubcortical (basal ganglia) circuitry, responsible for learned motor and social functions, may contribute to movement difficulties and social-communication deficits in children with autism.

Lloyd et al. (2013) described fine and motor difficulties in toddlers with ASD aged between 12 and 36 months. They emphasized the importance of addressing motor development in early intervention treatment. The research found that children with ASD present with gross and fine motor delays and atypical motor pattern (Landa and Garrett-Mayer, 2006; Vernazza-Martin et al., 2005; Berkeley et al., 2001). Ghaziuddin and Butler (1998) and Green et al. (2002) found motor coordination difficulties in children with autism and Asperger syndrome.

*Mental health comorbidity:* According to the DSM IV, 1994, individuals with ASD are likely to display one or more co-morbid disorders and symptoms, including hyperactivity, attentional difficulties, seizure disorder, mental retardation, depression and anxiety. A wide body of literature has studied the presence of anxiety in individuals with ASD (Tantam, 2000; Green et al., 2000; Kim et al., 2000).

Studies have shown that children with autism and Asperger syndrome present with an increased prevalence of psychiatric disorders, such as depression and anxiety (Lainhart, 1999; Howlin, 1997).

EEG abnormalities are common even in the absence of seizure disorders. Seizures may develop (particularly in adolescence) in as many as 25% of cases.

(DSM IV-TR, 1994, p. 72).

#### 1.4. Families with children with autism around the world

There is a promising body of literature on ASD and culture and “the question of whether ASD presents differently in different cultures has never been more pressing or more amenable to empirical investigation” (Mandy et al., 2014, p. 46)

Similar to all families, families with children who have autism vary considerably in terms of structural and functional aspects as well as cultural characteristics. In terms of research on families with children with autism, approaches differ considerably from country to country.

A few authors estimated the prevalence of ASD to be 2.64% in children aged 7–12 years in the general-population sample in South Korea (Kim et al., 2011). Other studies in Europe and North America have identified an average prevalence of approximately 1 per 100 (Ellefsen et al., 2007; Baird et al., 2006; Gilberg et al., 2006)

In Venezuela, a study conducted by Montiel-Nava and Peña (2008) reported a prevalence of 1.1 per 1000 for autism (children 3–9 years old).

The following examples from different countries provide an overview of cross-cultural studies relevant to the autism field.

At the European Autism Action Conference, Dublin, Ramirez (2010) pointed out that:

The amount of ASD research in central and Eastern Europe is small, as a result of limited funding and capacity. There is also a lack of research governance in this region of Europe. The evidence base for early and school-delivered interventions is poor or inconsistent in terms of reported outcomes.

For example, of the 27 EU (European Union) member states in Europe, each country reports different ASD prevalence, legislation, services available, and research capacity. The need for a broad policy for individuals with ASD across Europe may

improve conditions for people affected by ASD. When the European Commission Directorate for Health and Consumers (DG-SANCO) hosted a Panel of Experts in Luxembourg in March 2010, participants unanimously agreed that there is a need “to develop a public health policy for autism across Europe which is desirable, worthwhile and timely”.

The European Autism Public Health Alliance (EAPHA, 2010) recently estimated that with the total population in Europe at 500 million, the estimated ASD rate was thought to be 5 million, with an additional 5% (25 million) of the population affected, i.e., as family members (Ramirez, 2012). EAPHA (2012) identified further that the situation in terms of different treatment, legislative framework, access to services, family support systems, professional training, research, and educational systems differs vastly across Europe. For example, in *France*, the predominance of the psychoanalytical model creates confusion in diagnosis, mistrust toward parents and shows no progress.

In *Croatia*, early intervention programs started four years ago and only a small number of children with ASD are integrated in regular schools with support. Adults with ASD are still in schools after the age of 21 years because there is no adult care. Autism is not recognized in the legislative by the Ministry of Health, only by the Ministry of Education.

In *Estonia*, The Autism Diagnostic Observations Scale-Generic (ADOS-G) is not used as a diagnostic tool and there are no manuals on teaching children with ASD. Special support to children with ASD exists in education and only in larger cities since 2006.

In *Slovenia* the first centre for autism was created in 2005. In *Latvia*, the diagnosis of ASD was used only since 2006, before that mental retardation and schizophrenia diagnoses were used instead. There is no special program for ASD in special schools and there are no services for adults. Drugs have ceased to be the main treatment for ASD in the last three years.

In *Romania*, before 1989, autistic children were treated in the same way as children with intellectual disability. The assessment was done mainly in clinics, day-care centres and hospitals and they received pharmacological treatment. There were no programmes especially designed for children with ASD. At present, there are no data on the prevalence of autism cases in Romania. ASD in adults is not recognized by the law of persons with special needs and most adults with ASD are included in the mental disability category. Recently, the number of clinical cases diagnosed in Romania has risen and the Romanian adaptation of the two main diagnostic tools, the autism diagnostic interview–revised (ADI-R) and the autism diagnostic Observations scale-generic (ADOS-G) was published (Dobrea, 2010).

In countries outside of Europe, the picture is equally inconsistent. For example, in *Saudi Arabia*, Al-Salehi et al. (2009) found that autism was diagnosed later in girls than in boys and that about a third of the cases had a history of consanguinity. The findings relating to girls in their study suggest that ‘societal pressures to seek treatment may be less significant for girls as they are more easily hidden from external viewers’ (Al-Salehi et al., p. 343, 2009)

In *India*, Daley’s study (2002) showed that some families who have a child with autism chose to have another child for the explicit purpose of having someone to care for the child with autism after the parents’ death.

In *Greece*, (Stampoltzis et al., 2012) found that the average age of diagnosis was six years. They reported that there is insufficient and incomplete data on the exact number of Greek people with ASDs. Their study concluded that Greek pupils with autism seem to share common characteristics with pupils in other developed countries, confirming that autism is an international phenomenon.

In *Tanzania*, Mankosky et al. (2006) concluded that severe malaria, when contracted in the first few years of life, can cause autism. They described an infectious aetiology of autism and described that a logical consequence of the frequency of cases with infectious aetiologies is that the prevalence of autism should be higher in Africa than it is in the West. Children (21%) who had an entirely normal development through

the first two years of life acquired autism immediately after having severe malaria. The prevalence of autism in Africa is, however, unknown.

A recent study in the US state of New Jersey showed that “ASD prevalence is higher in wealthier census tracts, perhaps due to differential access to paediatric and developmental services” (Thomas et al., 2012, p. 202). The implications of assessment in different cultures could be linked to different assessment methods used in each culture. However, further research is essential into cultural influences on how assessment tools should be adapted in order to ensure comparability with measures used in other countries. The above studies show different perspectives in a number of countries around the world.



## 2. Family and autism

### 2.1. Families as systems

Most professionals, including family therapists, would agree that the family unit has the potential to offer support for its members. For example, Minuchin (1974) suggested that the family is the most efficient and effective way of helping, supporting, and influencing individual family members. Relationships within families are described as a ‘system’, where each member is affected by the experiences of others in the system through mutual interactions between family members. When a family system is compromised or jeopardized, distortions or modifications occur, thus clear and flexible roles are important for healthy family functioning.

Families are organized systems that have their own structure, dynamics, roles, communication styles. Most family therapists consider families as systems with mutually interdependent subsystems (Nichols and Schwartz, 2006; Cox and Paley, 2003). According to general systems theory (von Bertalanffy, 1968) family systems are characterized by:

- (a) wholeness and order, i.e., the whole is greater than the sum of its parts and has properties that cannot be understood simply from the combined characteristics of each part, (b) hierarchical structure, i.e., a family is composed of subsystems that are systems in and of themselves, and (c) adaptive self-organization, i.e., a family, as an open, living system that can adapt to change or challenges.

(Cox and Paley, 2003, p. 193).

In addition, Bowen (1993) emphasized that a change in one family member affects every other family member.

An analogy can be drawn between family systems and systems in other areas such as neuroscience. For example, William James (1890) introduced the proposition that the brain and its functions are not fixed, but are a system that responds to change. The

terms brain plasticity or neuroplasticity encapsulate this ability to adjust to external influences.

Cramer et al (2011, p. 1592) defined neuroplasticity as:

the ability of the nervous system to respond to intrinsic and extrinsic stimuli by reorganizing its structure, function and connections; can be described at many levels, from molecular to cellular to systems to behaviour; and can occur during development, in response to the environment, in support of learning, in response to disease, or in relation to therapy.

However, Cramer et al (2011) concluded that neuroplasticity does not always have a positive impact on behavioural status and can result in negative consequences in some cases.

By analogy, the family and its functions are not fixed and can change in terms of their structure, role, and connections. Families could be considered a complex “network”. Connections between family members are very complex. Any change that may occur in one family member could create different and new connections between family members; new functions can be adopted by different members. This can happen because of the “plasticity” function of the family. For example, in terms of family roles, in the absence of father’s figure and involvement, an older male sibling or uncle can substitute/adopt the father’s role.

In any family, all family members influence the whole family life, regardless of whether or not they reside in the family home. For example, when an adult offspring moves to a different town, this has a profound impact on the overall family dynamics and function. Of course, changes throughout a family’s life cycle bring opportunities, e.g. a younger sibling may cherish the fact that there is more space in the house, or challenges, e.g. an ageing parent may have to seek support elsewhere. McGoldrick and Carter (2001, p. 283) considered the family:

the most important emotional system we ever belong to ... As in any system, relationships and functioning (physical, social, emotional, and spiritual) are

interdependent, and a change in one part of the system is followed by compensatory change in other parts of the system. This makes the family our greatest potential resource as well as our greatest potential source of stress.

Using a systems approach, families with children on the autistic spectrum experience opportunities and challenges. A change that may arise in parents, such as ailing health or a change in employment status, affects different family members, including the child with ASD. Also, changes that arise in children with ASD, such as transition to secondary school or work, create change for parents and other members of the family. Figuratively speaking, the “plasticity” function of the family can adjust these changes that make homeostasis possible.

Collins et al. (2012, p. 84) described that:

all living systems are composed of subsystems in relationship with other subsystems. Family subsystems are often organized around gender, age and power...the success of the family is largely dependent of the parental subsystem.

Therefore, the parental subsystem is the most important subsystem within the family.

Parental subsystem, marital subsystem and children subsystem are a few examples of family subsystems. For example, a child belongs to various subsystems. The first subsystem is the parental subsystem as a child has with his/her parents/caregivers. The child’s parents belong to a marital subsystem. Then, a child may have brothers and sisters and this is the sibling’s subsystem. All these subsystems have their roles and connections.

Using a systems approach to the assessment of the relationship between a child’s diagnosis and family functioning, professionals may be able to identify families who are at risk and may also be able to evaluate the family’s adjustment process. Head and Abbeduto (2007) suggested that a family-system approach could be used to examine how culturally diverse families respond and therefore could be useful as a basis for assessment that can be integrated into the larger service-delivery system.

## 2.2. Types of families

Encyclopaedia Britannica (2012) describe the nuclear family as a group of people who are united by ties of partnership and parenthood and consisting of a pair of adults and their socially recognized children. Various categories and different concepts of families have been described in the literature. Cultural, social, economic and political factors make a contribution to current family structure and its functions. Modern changes in family structure and function lead to different types of families. Throughout history, the family has suffered major changes.

Collins et al. (2012) mentioned that all people come from a nuclear family. They categorised families as follows: family of orientation/family of origin, family of procreation, extended family, blended family/stepfamily, adoptive family, foster family and single-parent family. All these categories of families have an important role in raising a child with autism. Children with autism can be raised by biological family, foster/adoptive family, extended family, gay couples, single parent family etc.

Sprujit et al. (2001, p. 285) considered that, “families are not as stable as they used to be half a century ago. They are on the move.” Anthropological, psychological, sociological and historical research bring significant contributions to understanding families and changes that occur over time.

All family structures are vulnerable to structural changes. Family structural changes may have different implications for children. Research suggests that family structures have great impacts on the well-being of adults and their children (Amato, 2004; Ermisch and Francesconi, 2001).

According to attachment theory, children develop emotional connections to the major attachment figures (main caregivers) (Bowlby, 1969). The next chapter will explore more on this aspects. However, studies on attachment in children with autism are not clear on the issue of attachment.

### 2.3. Attachment and autism

Attachment, or the bond between a child and their caregivers that is developed through responsive caregiving and mutual affection, is thought to be a key element of healthy development (Bowlby, 1969). Autism is characterized by impairments in communication, social interaction and stereotypical interests and activities. Rejecting social interaction and having communication difficulties may impact the child and parent's ability to establish relationships and interactions within and outside the family and thus affect attachment adversely.

Kanner (1943) was the first who described the inability of children with autism to form affective contact. More than that, DSM-III (APA, 1980, p.87), describes that:

the failure to develop interpersonal relationships is characterized by a lack of responsiveness to and a lack of interest in people, with a concomitant failure to develop normal attachment behavior. In infancy these deficiencies may be manifested by a failure to cuddle, by lack of eye contact and facial responsiveness, and by indifference or aversion to affection and physical contact.

Most studies indicate that children with autism can develop secure attachment, while other studies demonstrate that they are not able to form secure attachment. For example, in a meta-analytic review, Rutgers et al. (2004) concluded that children with autism could form secure attachment and only the co-morbidity of autism and mental retardation was associated with attachment insecurity.

Despite these contradictions in the attachment literature regarding children with autism, it seems that children with autism display signs of attachment rather than developing fully secure attachment. Ainsworth et al. (1987) have developed the strange situation procedure to assess attachment relationships. They classified attachment as type A insecure-avoidant, type B secure attachment and type C insecure-resistant. Main and Solomon (1990) added type D – disorganized attachment.

Family needs should be taken into account both in terms of assessment and intervention planning. In most countries, there is a lack of adequate evidence-based services and families have to wait months or years before their child receives effective intervention (Keenan et al., 2007).

The knock-on effect for families of experiencing difficulties in obtaining a diagnosis and the delay in intervention is: confusion, isolation, frustration, conflict, and blame and high levels of family stress which can impact negatively on the ability of parents to engage with their child diagnosed with ASD (Konstantareas and Homatidis, 1992).

Starting with early stages, parents are very alert to their child's cry, smile, and emotions. For example, crying is a communication method used by children with their parents. Misunderstandings in communication during early stages can impact on the relationship between parents and children (LaGasse et al., 2005). Esposito and Venuti (2008) suggest that parents often did not understand the reason for crying in their autistic children and showed difficulties in understanding their children's needs. As a result, parent's reactions to autistic crying was different than crying experienced by parents of children with intellectual disability (ID). The results highlight a link between autism and expressing and sharing emotions.

Thus, crying could be considered an early sign of risk during the first stages of life that is crucial in a child's development. Crying is an important indicator in the assessment of children with ASD. It is often reported by parents of children with ASD that their child's cry is different, they don't cry when they are hurt, they display an inexplicable cry and so on. Research has shown that children with ASD tend to be less secure and more disorganized, and their involvement with the parents during play was lower. (van IJzendoorn et al., 2007). In this study, more sensitive parenting was not associated with more attachment security.

Given that communication and social interaction are core deficits in children with autism, two-way communications (verbal and non-verbal) and be affected adversely in families with children with autism. Siller and Sigman (2002) found that children with ASD whose caregivers showed higher levels of verbal responsiveness

developed better language skills. Venker et al. (2012) agree and give evidence that parent verbal responsiveness is associated with positive child language outcomes.

Family communication is an important factor in terms of family functioning. Communication with children, communication between members of a family, and communication with other parents or professionals are ways to achieve a well-functioning family. Patterson et al. (2012) suggested that parent's education and training programs should be designed to enable parents to support the development of their child's language and communication skills. Families should be viewed as a real resource and engaged as co-therapists (Matson et al., 2009; Munteanu, 2009). Including parents as co-therapists for their children has shown to be beneficial in terms of improving their child's development.

Communication is an important factor for families and children with autism. The nature of family communication can either be cooperative, and collaborative thus offering a resource for the coping mechanisms and problem solving within families or non-cooperative and thus creating a source of stress, conflict, and family dysfunction. Of course, during challenging times, such as when families are adjusting and may experience additional internal and external difficulties as that their child is diagnosed with a disability, constructive patterns of communication are particularly important (Olsen et al., 1999).

Within the family system, parent-child relationships play an important role in the development of children's language skills because language development occurs within reciprocal interactions between adults and children. Of course, the characteristics of the parents and the child influence communication skills and each person's ability to respond. Patterson et al. (2011) examined the impact of parenting training designed to develop communication and social interaction skills of children with ASD. They report an increase in child communication and social outcome as parents demonstrate an increase in their own abilities to communicate.

Siller and Sigman (2002) were the first to examine the relationship between parenting style and the development of children diagnosed with ASD. They found a strong link between parental interactions with the child/ren's communication skills.

Others demonstrated that parenting behaviours directly impact on child behaviour problems in children diagnosed with ASD.

Helping parents to manage their parenting style and parenting behaviours, as well as their parenting stress, may enhance their management of their child's behaviour problems. (Osborne et al., 2008, p. 260).

Children with autism have difficulties in reciprocity in social interaction. Many studies focused on attachment behaviour in children with autism and attachment difficulties (Dissanayake and Sigman, 2000; Bernabei et al., 1998; Buitelaar, 1995; Capps et al., 1994).



## 2.4. Psychological well-being of parents of children with ASD

Only a few studies have examined the psychological functioning and well-being of parents of children with ASD. Parents may experience diverse individual, familial and social situations. Parental well-being should be considered an indicator of how families are facing the fact of having a child with autism.

Parents of children with ASD are at increased risk of experiencing negative psychological difficulties. Mothers of children with ASD experience high levels of psychological distress which is correlated with high levels of child behavioural difficulties and low levels of support in the family (Bromley et al., 2004). Lloyd and Hastings (2009) examined “hope” as a construct that could be helpful to increase familial well-being. This could be a protective factor which might influence parents’ health.

A vast number of studies have examined differences in raising a child with autism and raising a child with Down syndrome or other type of disability. One of these studies (Ogston et al., 2011) suggested that mothers with higher hope reported less worry. Mothers of children with autism had lower hope and more future-related worry than those whose children had Down syndrome.

There is evidence that the level of stress in families with children diagnosed with ASD is higher than in families with children diagnosed with other disabilities or families without disabled children (Duarte et al., 2005; Honey et al., 2005; Sivberg, 2002; Weiss, 2002; Dunn et al., 2001; Konstantareas, 1992). These stress factors can produce a range of problems for parents and cause disruption in family life (Dunn et al., 2001).

Learning that a child has a developmental disability is a stressful and difficult process (O’Brien, 2007) and parents of children with disabilities experience more depressive symptoms (Noh et al., 1989) and higher levels of stress than parents of typically developing children (Sivberg, 2002; Dunn et al., 2001; Rodrigue et al.,

1990; Kazak and Marvin, 1984). In addition, parents may experience anxiety, fear, and guilt (Gray, 1994).

Benson and Karlof (2009) found that stress proliferation among parents of children with ASD over time is the main contributor to parental depression. Stress factors are linked with poor mental health for mothers of children with autism (Montes and Halterman, 2007). Stress factors could contribute to parent's ability to support their children. Osborne et al. (2008) highlighted that greater levels of family stress may reduce the efficacy of home-based, early teaching interventions.

Findings from a recent study suggest that:

family level adaptability may influence the course of maternal depression and child behaviour problems in families of adolescents and young adults with autism, above and beyond the potential contribution of the mother– child dyadic relationship. (Baker et al., 2011, p. 605)

Wachtel and Carter (2008) highlighted particularly the role of mothers during the diagnosis stage and mothers' perceptions about diagnosis and intervention and suggested that, “parents of children on the autism spectrum face a unique set of challenges that, not surprisingly, impact on their psychological adjustment” (p. 575).

Another recent study (Shur-Fen Gau et al., 2012) investigated the psychopathology, marital relationship, and family function in parents of children with autism and parents of typically developing children in Taiwan. Findings demonstrated that both parents of children with autism displayed more psychological problems, marital difficulties and family dysfunction. In addition, mothers of children with autism showed more psychopathology and maladjustment than did the fathers. Mothers of children with autism also showed less marital satisfaction, affection expression, family adaptability and cohesion, compared to mothers of typically developing children.

## 2.5. Family functioning

In general, family functioning is described as the way in which family members are emotionally linked with each other, how they communicate and respond to problems (Epstein et al., 1978). It is clear that family functioning is crucial for a child's well-being. Increasingly, a number of research studies are focusing on the effects of ASD on family functioning (Honey et al., 2005; Bromley et al., 2004; Noh et al., 1989; Gray, 1994). On the other hand, research is examining the influences of family on children with ASD (Osborne et al., 2008). As a result, family functioning implies a two-way functioning or circularity, the cause and effect rule. Family functioning includes interactions between family members.

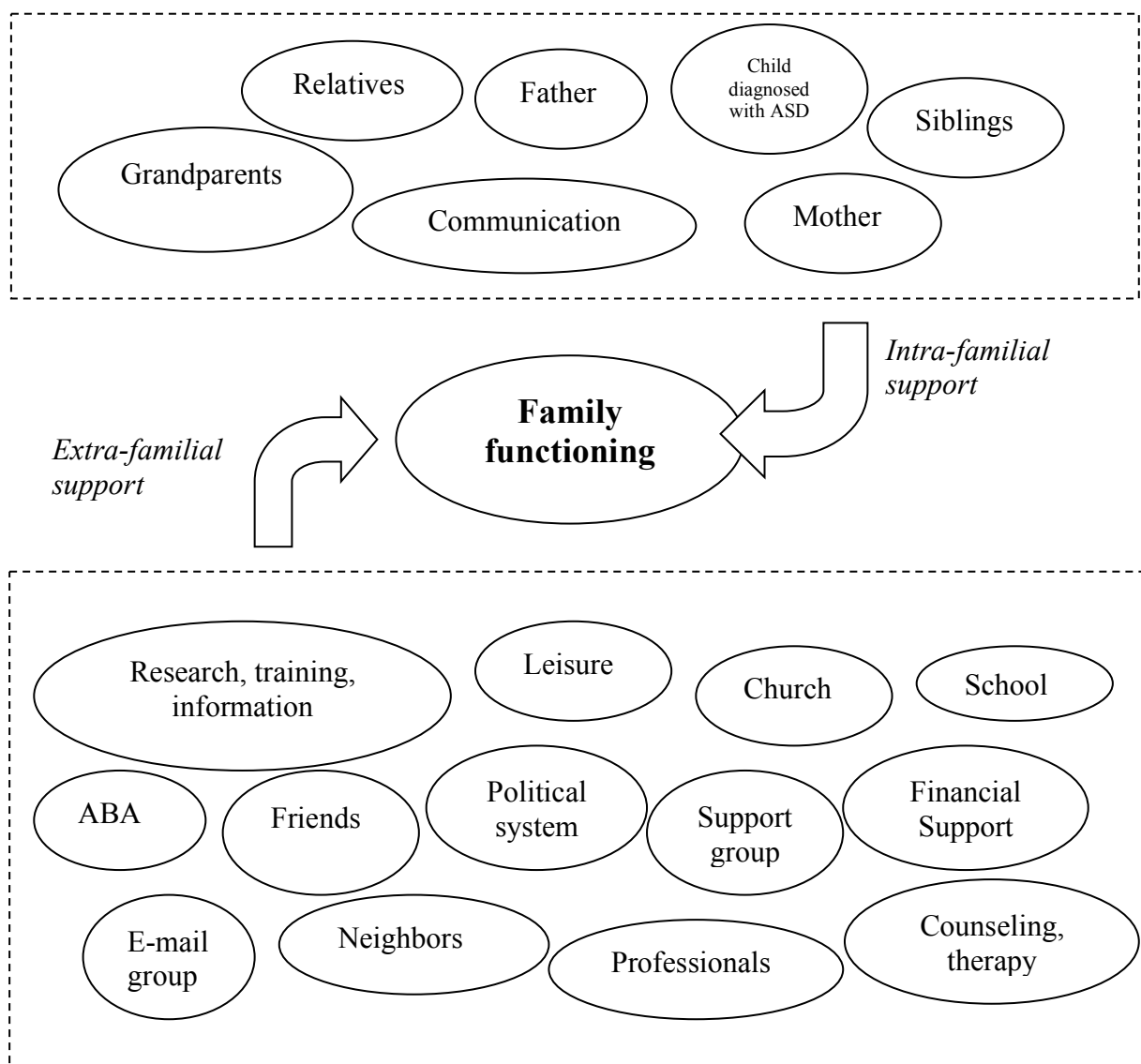
Higgins et al.'s (2005) study provides an overview of the negative effects of having a child diagnosed with ASD on family functioning. They concluded that families who are not engaged in joint activities with both the child diagnosed with ASD and other siblings tend to score low on measure of family functioning, family connectedness, or responsiveness to family members' needs. Their study provided a view of the potential for negative effects of having a child diagnosed with ASD on family functioning.

A well-functioning family depends on good extra-familial support and intra-familial support and the same is true for families with children diagnosed with ASD (Munteanu and Dillenburger, 2009). Intra-familial support includes: communication, interaction, cohesion, and adaptability between mother, father, child, siblings, grandparents, and other relatives. Extra-familial support includes professionals, political/legislative system, school, effective intervention, i.e., ABA (applied behaviour analysis), research/training/information, friends, church, leisure, e-mail group, support group, neighbours, financial support, counselling/therapy.

While there are individual differences in family and support network structures (e.g. single parent families), if a substantial number of supports are not present or functioning well, families are likely to experience difficulties (Minuchin and Fishman, 1981). A picture emerges of support necessary for families to function well

(Rodrigue et al., 1990). Figure 2.1 shows a diagrammatical outline of support factors that are important for an effective family functioning (Munteanu and Dillenburg, 2009)

Figure 2.1: A model of family functioning (Munteanu and Dillenburg, 2009)



Family communication is an important factor related to family functioning. Communication with children, communication between members of family, communication with other parents or professionals are ways to achieve a well-functioning family. The nature of family communication can either be positive, cooperative, and collaborative thus offering a resource for the coping mechanisms

and problem solving within families – or negative and non-cooperative and thus creating a source of stress, conflict, and family dysfunction. Of course, during challenging times, such as when families are adjusting and may experience additional internal and external difficulties because their child is diagnosed with a disability, good and constructive patterns of communication are particularly important (Olsen et al., 1999).

The functioning of families with children diagnosed with ASD depends on intra-familial and extra-familial support systems. In order to understand family function fully, these support systems must be analysed structurally and functionally, including an assessment of family needs, sibling subsystems and family support. It is clear that parents, children, siblings, and grandparents need support, particularly during the diagnosis process. This support should be tailored to family needs, family functioning, and the services available.

To date however, there is a lack of empirical data on family functioning in general and in particular in relation to different cultural, ethnic, socioeconomic backgrounds and family configurations. Such information would be useful in understanding family needs and to help these families during the diagnostic process (Nissenbaum et al., 2002) especially since the experience of families during the diagnostic process is different for each member of the family, including the child/ren diagnosed with autism, siblings, parents, grandparents, and other relatives. Few studies have examined family functioning and family needs during the diagnostic process, influences of assessment process, service provision, social support networks, and other stressful life events on family functioning during the diagnostic process.

The impact upon families of having a child with an ASD has been explored in general (Wing, 1997) and there is a growing body of literature to suggest that chronic illness and disability negatively impact on family functioning (Williams and Bond, 2002).

In the last decade, research has focused on the effects of a diagnosis of ASD in a child on a couple's relationship. For example, Myers et al. (2009) found that mothers of children with ASD showed significant relationship strain. Another study,

conducted by Higgins et al. (2005) found that mothers of children with ASD experienced lower levels of marital happiness. Brobst et al. (2009) found that couples with a child with ASD experienced lower levels of relationship satisfaction.

Hock et al., (2012) explored the ways in which parenting a child with ASD may influence the couple's relationship. Their findings suggest that parenting a child with ASD created many demands and emotional responses that put extraordinary pressure on the couple relationship and subsequently changed the ways that partners related to each other. The ASD served as a crucible for the couple relationship, mainly during the early years following diagnosis. Conflict and distance continued and then couples often experienced deeper intimacy and commitment.

Altieri and Von Kluge (2009) identified five challenges that emerged from family's experiences in raising a child with autism: development, questioning, devastation, solutions, and growth. They described the family's struggles, confusion, devastation, loss after they received the diagnosis (negative experience) and afterwards they described their positive experience in raising a child with autism and a focus on helping their child.

## 2.6. Coping strategies

Coping strategies are important in determining whether stressful experiences lead to adaptive or maladaptive results. Stress negatively affects people's functioning and health. How people respond to stress is called coping behaviour.

As family circumstances are not identical, coping strategies in parents of children with autism may be different. Parental coping strategies may vary from country to country, as coping is considered to be dependent on the context (Carver et al., 1989). Nonetheless, many families have enough strategies to cope with different demands of raising a child with autism.

Coping is defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus and Folkman, 1984, p. 141).

Lazarus and Folkman (1984) suggested two main coping strategies: emotion-focused and problem-focused. Problem-focus strategy involves actions to remove stressors. Emotion-focused strategy involves actions or thoughts to control feelings that result from stressful circumstances.

Parental coping mechanisms have changed over time as there are different internal (intra-familial) and external (extra-familial) factors which may affect family adaptability of raising a child with autism. Having a child with autism and trying to manage daily living demands could impact parents' ability to adapt to different circumstances. Sivberg (2002) emphasized the importance to help parents develop and use adequate coping behaviours, so as reduce the strain on the family system and to enable them to meet both their own needs and their children's needs.

In the absence of clear aetiology and the lengthy period of treatment, families with children with ASD have to adapt and cope with their current situation. Based on this, their coping strategies could vary. Gray (1994) in a qualitative study showed that most parents use a variety of coping strategies which include: the use of service

agencies, family support, social withdrawal, religion, normalization, individualism and activism.

A few years later, Gray (2006) added that coping strategies changed from the time of the initial study, as more parents coped through their religious faith and other emotionally-focused strategies. Various studies have identified coping strategies for parents of children with ASD. For example, emotionally-focused coping strategies was found to help parents of children with ASD. Dabrowska and Pisula (2010) found that the use of emotionally-focused strategy can adjust parental stress. Altieri and von Kluge (2009) evaluated familial variables of cohesion, adaptability and social support which contributed to coping in the family unit and provided support for parents.

Pottie and Ingram (2008, p. 856) hypothesized that:

increased use of problem-focused, seeking support, emotional regulation, compromise, and positive reframing coping would predict lower levels of daily negative mood and higher levels of daily positive mood.

By using these coping strategies, parents show less stress.

Other studies show that some coping strategies are often unhelpful in coping with the demands of raising a child with ASD. Hasting et al. (2005) suggested that four coping dimensions are relevant to parents raising a child with autism: active avoidance coping, problem-focused coping, positive coping and religious coping. Problem focused coping and positive coping were not associated with parental stress or mental health in their study, while active avoidance coping and mixed religious coping and the denial factor were related to stress and mental health problems in both mothers and fathers of children with autism.

Some studies explored how a positive perception of a child with a disability can improve the parent-child relationship and help parents to cope with the daily tasks of raising a disabled child. In their study, Wachtel and Carter (2008) highlighted that maternal acceptance and the sense of resolution about their child's diagnosis of ASD,



led to the mother's engagement in child's play and attention, greater reciprocity and mutual enjoyment. A positive perception of a child with disability can help parents to cope with stress (Hasting et al., 2002).

Coping strategies vary as family structures and circumstances are not identical. Coping strategies of mothers and fathers of children with autism have been examined in many studies. Mothers of children with ASD report more stress than fathers (Duarte et al., 2005; Hastings, 2003; Weiss et al., 2002). Thus, mothers and fathers have different ways of coping with stress but this requires further research (Hastings, 2005).

Wang et al. (2011) conducted research in the Republic of China and found that the most frequently coping strategies used by parents of children with autism were: acceptance, active coping, positive reinterpretation and growth, suppression of competing activities, and planning.

Mak and Ho (2007) examined mothers' perception in raising a child with an intellectual disability in Hong Kong and the coping strategies used by mothers. Their findings suggest that the main coping strategy used by mothers was relationship-focused coping.

Pisula and Kossakowska (2010) examined the relationship between a sense of coherence (SOC) and coping strategies in parents of children with autism and parents of typically developing children. They found that escape-avoidance coping was employed more frequently by parents of children with autism. Their findings showed that the higher the level of SOC, the more likely parents are to use coping by seeking support and make efforts to regulate their feelings and actions (self-controlling coping). They recommended that parents need to be supported in developing strong SOC, which could reduce the tendency to use the strategy of coping by self-blaming.

Smith et al. (2008) suggested that for mother of toddlers with ASD, lower levels of emotion-focused coping and higher levels of problem-focused coping were generally associated with better maternal well-being in relation to child's level of

symptomatology. For mothers with adolescents with ASD, coping often acted as a buffer when autism symptoms were high.

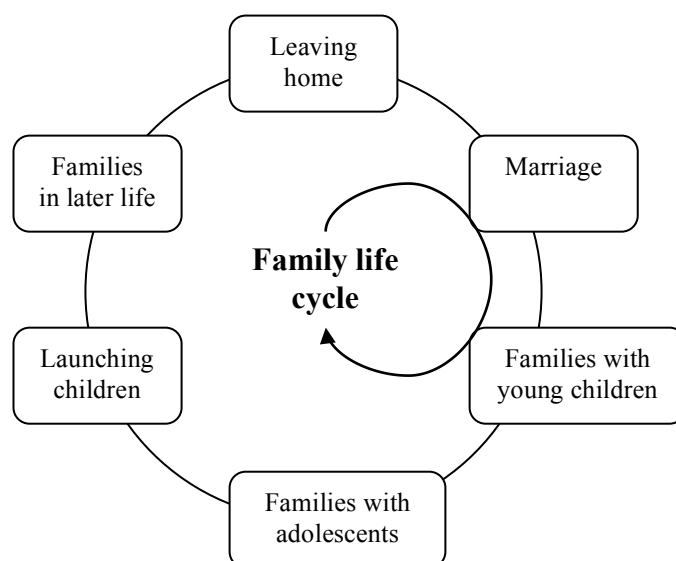
### 3. The Family Life Cycle

According to Kapinus and Johnson (2003) “the family life cycle is a theoretical tool whose utility can be assessed only in the context of meaningful propositions about the nature of family life” (p. 157). Not surprisingly then, the attempt to describe an entire family life cycle is made difficult by the complexity of family systems and the multitude of internal and external variables.

Most descriptions of the ‘stages of family life cycle’ are based on children’s presence/absence in the family. Of course, cultural differences have to be taken into account, for example, the family life cycle of a Romanian family differs to that of a family in Ireland due to the differences in terms of customs of marriage and child rearing.

McGoldrick (1988) proposed the main family life cycle stages of American middle-class families (Figure 3.1): Leaving home, marriage, families with young children, families with adolescents, launching children, families in later life.

Figure 3.1  
Family life cycle stages



Clearly, not all families go through all of the proposed stages of the family life cycle. For instance, family without children obviously does not have distinct child-related stages and families with children with disabilities may not “launch children”. As mentioned earlier, not all couples decide to get married and there are single-parent families as well as families based on same-sex partnerships. The stages that involve children can be very different between families, especially where families include children with autism.

Children with autism bring very specific challenges into a family and the traditional idea of family life cycle stages has to be reviewed and adjusted.

### 3.1 Families with young children with autism

There are many events when the child with ASD is young that affect families, such as becoming a parent, receiving the diagnosis, coping with diagnostic process and its implications. Families generally experienced high levels of stress during the diagnosis process (Stuart and McGrew, 2009) across three domains, the individual caregiver, the marital relationship, and the family as a whole. Families can adopt different coping strategies to manage daily difficulties and stress in raising a child with ASD.

There is evidence that the level of stress in families with children diagnosed with ASD is higher than in families with children diagnosed with other disabilities, or in families with children without a disability (Honey et al., 2005; Duarte et al., 2005; Sivberg, 2002; Weiss, 2002; Dunn et al., 2001; Konstantareas, 1991). Diagnosis is a decisive moment for parents and children in terms of early intervention services for children and level of acceptance and adaptation for parents and the entire family. Clearly, families are vulnerable during this process and may experience difficulties in adjusting. Families who are not well supported may risk higher levels of dysfunction in subsequent years (Minuchin, 1981).

Sometimes parents are not satisfied and have doubts about the initial diagnosis and seek a second opinion (Osborne and Reed, 2008; Mansell and Morris, 2004; Howlin, 1999; Midence and O'Neill, 1999). This can lead to negative feelings and lack of trust of the professionals concerned (Brogan and Knussen, 2003). In any case, until diagnosis is complete and the child has been correctly diagnosed, parents go through a very stressful period. In fact, Hutton and Caron (2005) suggested that the family as a whole, including parents, siblings, grandparents, is greatly affected by the diagnosis.

Therefore, helping parents, siblings, and grandparents, understand what it means to be diagnosed with ASD and what the implications are, could be the best support. This way, parents have the opportunities to discuss their worries about their child and assess the available services.

A family develops a parent role when their child is born. This role involves many demands when parents are told that their child has ASD. During this family life cycle, parents are experiencing the whole process of diagnosis and its implication which is largely discussed in this study. Currently there is an increase need for services for children on the autistic spectrum, both for assessment and intervention. Parents may need to familiarize themselves with terminology and concepts and they need support from the very early stages of diagnosis. Families differ significantly in terms of their perception about becoming a parent of a child with ASD. For example, some families may become very involved in their child's pathway and some of them may not.

The diagnosis of ASD is a stressful experience for a family. For some families, the diagnosis can be a relief, as they finally have an explanation for their child's difficulties. Bloch and Weinstein (2009) indicate that it is important to underline that during the period of diagnosis, "the family system does not always function optimally or in ways that meet the needs of all its members" (p. 25).

The impact of ASD diagnosis on siblings differs according to their age, and the effect on them is related to the family's response. Siblings may experience various feelings in relation to their brother/sister with ASD. Parents may consider support for siblings, such as support groups (sibshops). On the other hand, the literature suggests that "there is an increased risk of autistic disorder among siblings of individuals with the disorder, with approximately 5% of siblings also exhibiting the condition. There also appears to be risk for various developmental difficulties in affected siblings" (DSM IV-TR, 1994, p. 73). Similar to siblings, grandparents also react to their grandson/granddaughter's ASD diagnosis. The impact of ASD on grandparents could be perceived differently if grandparents live with the family.

Differences in levels of stress during diagnosis seem to depend on parental gender, severity of autism, and levels of social/familial support. In general, family reactions to diagnosis include: shock, denial, blame, shame, and anger (Baba et al., 2004) and the depth of these reactions is related to the severity of autism. Mothers of children diagnosed with ASD experience most stress during the diagnosis process, although

the level of stress is lower if mothers receive support from their partners and relatives. Support from professionals can also help families to cope with stress (Kazak and Marvin, 1984).

### 3.2 Families with adolescents with autism

Parenting adolescents generally is not easy as most families experience challenges based on adolescent behaviour and development. For families with adolescents and adults with autism, parenting is a lifelong commitment. Seltzer et al. (2000, p. 87) demonstrated that

in adolescence, many families recognize that their child's level of functioning or capacity for independence may not change dramatically in the years ahead... The task of parenting a person with autism throughout the first two decades of life is marked by extraordinary effort, major accommodations in the family's daily life.

DeMyer et al. (1973) found that of 120 adolescents with autism, 58% lived with their parents into adulthood.

Orsmond et al., (2009) investigated sibling relationships and well-being in adolescents and adults with a sibling with ASD. Their study indicate that parents play an important role in siblings' perceived relationship quality with their brother or sister with ASD, in adolescence and in adulthood. Adolescents reported more positive effects in their sibling relationship when their sibling with ASD had fewer behaviour problems; and greater use of problem-focused coping which buffered the negative effects of behaviour problems on sibling engagement.

Being bullied by peers is a major difficulty in adolescence. Research has indicated that individuals with ASD may experience higher rates of bullying and they are at greater risk of victimization than their peers (Cappadocia et al., 2012; Rowley et al., 2012; van Roekel et al., 2010)

Hellemans et al., 2007 found that subjects with ASD display some kind of sexual behaviour and masturbation was often common. In this study, the number of bisexual orientations was high; ritual sexual use of objects and sensory fascinations with a sexual connotation were sometimes present. Paraphilia was present in two subjects.



The study has shown that adolescents with ASD need sex education courses regarding their sexual behaviour.

Parenting an adolescent with autism can be difficult and challenging for parents and other caregivers. The effects of ASD on the family unit can change from childhood to adolescence as parents of children with ASD encounter difficulties in managing their child's challenging behaviour. The research found an increase in symptoms during adolescence as the child grows up (Norton and Drew, 1994; Bristol and Schopler, 1983;).

Research in autism focused on self-determination in adolescents with autism (Field and Hoffman, 1999). Their study found that family has an important role in the development and expression of self-determination due to difficulties in communication and social relationship in individuals with autism.

Research found that the transition from school to adulthood for youth with ASD can be particularly difficult for many adolescents, especially in the areas of education, employment, community living, and community integration.

Although some individuals with ASD are able to successfully transition, most are faced with significant obstacles in multiple areas as they attempt to negotiate their way into college, work, community participation, and independent living.

(Hendricks and Wehman, 2009, p. 77)

A particular difficulty for parents of children with autism can be the transition of their child from childhood to adolescence/adulthood. The child's future is the main concern for all parents. As a result, parents of children with ASD can be worried about if their child can work, live independently, get married or attend college. The literature suggest that adolescents and adults with ASD need training and education in order to integrate and work (Gerhardt and Holmes, 2005)

### 3.3 Launching children with autism and families with children with autism in later life

Probably the most important question that parents with children with autism ask is in relation to their child's future. While the causes of autism spectrum disorder (ASD) still are not fully understood, parents of adults with autism may create their own explanations of this disorder. More than that, parents "construct a sense of understanding about their life as a caregiver that supports them in their ongoing care role" (Hines et al., 2012, p. 16).

Although the quality of life of adults with autism has improved over time, the majority of them continue to be dependent on their family and other forms of support. Hare et al. (2004) found that the majority of participants in their study expressed some form of restriction on their lives, mainly the limitations to their social lives and expressed concern about the future of their son/daughter. Billstedt et al. (2011) found that the majority of people with autism remained dependent on parents or caregivers for support for their education, accommodation and occupational situation.

Howlin et al. (2004) stated that:

although a minority of adults had achieved relatively high levels of independence, most remained very dependent on their families or other support services. Few lived alone, had close friends, or permanent employment. (p. 212).

For those who were in employment, jobs were poorly paid and did not provide enough support for independent living. The level of intellectual functioning in childhood and IQ (intelligence quotient) scores at least on non-verbal tests seems to be associated with positive outcomes, and individuals with IQ level of above 70 are likely to do better than those with a lower IQ (Howlin et al., 2004). Dillenburger and McKerr (2011) explored issues that older persons who care for their adult

sons/daughters with disabilities may have. Their findings show lack of support, respite care and future planning are all issues that causes stress for caregivers.

Matson et al. (2009) suggest that the effect of ASD on adaptive independent living skills makes it difficult for many adults with ASD to live independently. The deficits specific to ASD, especially the adaptive functioning (communication and social skills) make it difficult for many people with ASD to live independently. These authors assessed 234 adults with ASD or pervasive developmental disorder-not otherwise specified (PDD-NOS) and intellectual disabilities (IDs) with respect to the nature and extent of their independent living skill functioning. Matson et al. (2009) concluded that

[i]n general, the autism group evinced the highest impairment in adaptive functioning. Individuals in the PDD-NOS group exhibited less impairment, while adults with ID only showed the least impairment. Thus, as ASD symptoms increase, it appears as though adaptive behaviour capacity decreases. (p. 1206)

The effects of autism may affect the mutual relationship between parents and their son/daughter and the closeness between parents and their son or daughter with autism in later life (Greenberg et al., 2004). Lau and Peterson (2011) explored romantic attachment style, marital satisfaction and parenthood satisfaction in 157 Australian men and women with Asperger syndrome. They found that marital satisfaction was high and adults with Asperger syndrome presented with insecurely avoidance in romantic attachment.

Very little is known about the effects of ASD on the family unit in terms of living arrangements. Adults with ASD can live in residential settings, or they can live with their parents or other caregivers, or they can live independently. However, the child's future remains the main source of concern for parents after they are diagnosed.

#### 4. Children with autism and their families in Romania

The following two chapters (4 and 5) describe Romanian and Irish families of children with ASD from different perspectives, such as: *historical and family aspects, political/legislative, assessment/diagnosis and service provision*. Ireland and Romania are two European countries with many similarities and differences that need to be described in order to understand the uniqueness of each country with regard to children with ASD and their families. A large number of studies have been conducted in Europe but only a few in Romania and Ireland. Because of the lack of published literature and studies in both countries, the chapters may not reflect the real situation of children with ASD in Ireland and Romania.

##### 4.1. History and demographic aspects

Romania with a population of approximately 21.5 million joined the European Union in 2007 and has experienced an economic boom, although it is obviously affected by the present economic downturn. Religion is important for Romanian people; the primary religion in Romania is Christian Orthodox. Romania has faced a crisis concerning childcare, especially in regard to abuse and neglect of the most vulnerable children in institutional care especially during the communist era.

Little is known about children with ASD in Romania (Munteanu and Dillenburger, 2009), apart from the fact that children with disabilities generally were institutionalised until, after the end of communist rule in 1989, when gross overcrowding, underfunding, and neglect of institutionalised children was uncovered. In an effort to remove obstacles to entry into the European Union, Romania closed most of its large children's homes. Since then, Rutter et al. (1999) found "quasi-autistic patterns" or as Hoksbergen et al. (2005) puts it, "post-institutional autistic syndrome" in Romanian children who were adopted in the UK. In Romania, Autism Romania (founded in 2001) aims to raise awareness and to "protect the rights and interests of persons whose life is marked by autism, increased quality of life and promoting their full inclusion and participation in community life to which they

belong” (Autism Romania, 2009). The emphasis is on awareness raising and policy change rather than onearily intervention. Haiduc (2009, p. 27) considered that “children with autism are invisible in contemporary Romanian society; there is even a lack of statistical data regarding children with autism in Romania”.

Traditionally, family structure and functioning in particular with regard to composition, gender roles, communication, and values were similar in Romania and Ireland, but this has been affected by rapid changes in both countries, e.g. single parenthood has risen in both countries; gender stereotypes are becoming less pronounced. Gavreliuc (2012) conducted research in Romanian with the aim of investigating whether the Romanian revolution of 1989 has changed the Romanians’ values and attitudes. The aim of his study was to examine patterns in the distribution of values and attitudes for three generational cohorts in contemporary Romania: the “younger” generation (M = 26 years), almost exclusively socialized during the period after the collapse of communism; the “middle” generation (M = 41 years), socialized both during and after communism; and the “older” generation (M = 56 years), exposed to extensive socialization during communism. Based on the differences in the exposure to communist or/and democratic regime and its multifaceted consequences in these three cohorts, results indicated a “conservation of attitudes and values, revealing relevant similarities in the axiological and attitudinal profiles among the two peripheral cohorts (the younger and the older generations)” (Gavreliuc, 2012, p. 190). Gavreliuc (2012) concluded that the collapse of communism brought considerable changes at a social, political and behavioural level; however, little changes occurred in the profound mental structures (attitudes, especially values).

#### *Demographic aspects Romania-Timisoara*

In terms of the demographic aspects of Timis County, Romania, in 2001, the Regional Statistics Timis showed that the total population of Timis County was 683,540. The total population of Timisoara City was 319,300. A total of 44% of the population is married, 38.3% have primary-level education, 42.3% have secondary-level education and 19.2% have a bachelor’s degree. In October 2011, children between 0–14 years were 13.8% of total population.

Based on the statistics from the Direction for Protection of People with Handicap (Direcția pentru Protecția Persoanelor cu Handicap), in March 2012, the total number of people with disabilities in Romania was 687,596; 60,353 (8.8%) were children and 627,243 (91.2%) were adults. The results show that 49.6% of children have a severe disability (grade I), and mild and medium 20.2% and 28.6% (grade II and III). The rest of the children (2%) have a very mild disability (grade IV).

Recent statistics from the National Authority for People with Handicap, show that in March 2013 the total number of children with disabilities in Romania was 8.7%. In Timis County, the total number of children with disability was 61,063.

#### 4.2. Legislative framework for children with autism

The most recent legislation in Romania “Legea nr. 151/2010” includes specialized services for children with ASD. However, diagnostic criteria do not include adults in Romania. Thus, in Romania, there are no published statistics on the number of children or adults diagnosed with ASD.

The aim of the Legal Act for Persons with ASD (“Legea nr. 151/2010, Art. 1.”) is to provide specialized health, educational and social services for person with ASD. These services need to be provided by a multidisciplinary team.

##### Chapter I

Art. 1 emphasizes the early diagnosis, intervention and improvement of quality of life and social functioning of persons with ASD.

Art. 2. Integrated specialized services (health, education and social areas) include: early diagnosis, clinical psychiatric diagnosis and clinical psychological assessment, psychopharmacological treatment, specialized early intervention, cognitive-behavioural therapy, parental and family counselling.

Art. 3. – (1) The multidisciplinary team includes child psychiatrist, clinical psychologists, psychotherapists, psycho-pedagogues, speech and language therapists, physiotherapists, teachers and social workers.

Art. 3. – (2) Ongoing monitoring is implemented by child psychiatrists, clinical psychologists, psychotherapists in both public and private health services.

##### Chapter II

Art. 4. – (1) Early diagnosis is organized for children between 0-3 years of age, according to the methodological standards of present legislation.

Art. 4. – (2) All persons with ASD have free access to integrated specialized health, educational and social services.

Art. 5. Early diagnosis and integrated specialized health, educational and social services for persons with ASD are offered by professionals who are members of the Romanian Medical College and the Romanian College of Psychologists.

Art. 6. The Minister for Health, The Minister for Education, The Minister for Work, Family and Social Protection and the nongovernmental organizations responsible to provide mental health services, develop protocols of collaboration in order to improve integrated health, educational and social services for persons with ASD.

### Chapter III

Art. 7. According to the Romanian College of Psychologists, integrated specialized health, educational and social services for persons with ASD are implemented by child psychiatrists and clinical psychologists.

Art. 8. Romanian Medical College, Romanian College of Psychologists and Romanian Federation of Psychotherapy are implementing specific standards in psychotherapy for people with ASD.



#### 4.3. Assessment and diagnosis

In Romania there are no statistics or prevalence studies. However, Gliga and Gliga (2010) estimated that in Romania there are approximately 200,000 people affected by autism.

Different internationally recognized assessment tools are being used to assess children with ASD. Romanian children who participated in this study were diagnosed with ADOS-G and other standardized tools for ASD diagnosis. As mentioned previously in this research, in Romania, before 1989, autistic children were treated as same as children with intellectual disability. The assessment was done mainly in clinics, day-care centres and hospitals and they received pharmacological treatment. There were no programmes especially designed for children with ASD. At present, there are no data on prevalence of autism cases in Romania. ASD in adults is not recognized by the law of persons with special needs and most adults with ASD are included in the mental disability category. Recently, the number of clinical cases diagnosed in Romania has risen and the Romanian adaptations of the ADI-R and ADOS was published (David et al., 2013; Dobrean, 2010).

Similarly to Ireland, there is no consistency regarding the assessment of children with ASD, as the assessments are conducted in both public and private sectors. At present, in Romania, children with ASD are diagnosed in hospitals, and in public and private agencies. In Romania, the general practitioner (*medic de familie*) has a key role in referring children with developmental delays to a specialized service, hospital, or private child psychologist/psychiatrist.

The medical model is central in the assessment of children with ASD in Romania. All children need a medical certificate from a consultant in order to access benefits and entitlements. In Romania, the time scales for diagnosis are not described in the literature.

#### 4.4. Services available for children and families

Early intervention services, including speech and language therapy, occupational therapy, physiotherapy, applied behaviour analysis-based interventions are internationally recognised as being vital for children with autism. However, family experiences in accessing specific services for a child with ASD are unique and the lack of services, long waiting lists, small numbers of professionals such as ABA tutors, are just some of obstacles families accessing services for their children face.

In Romania, parents can access very quickly assessment and intervention services for children with ASD. No published literature was found regarding parents accessibility to services in Romania. As mentioned, in Romania, no published statistics exist regarding the number of children or adults diagnosed with ASDs.

While in Ireland there is some science-based provision for treatment, although it is limited (Keenan et al., 2007), in Romania there is no provision for scientifically validated basis of treatment, i.e. ABA (Munteanu, 2009).

## 5. Children with autism and their families in Ireland

### 5.1. History and demographic aspects

The Republic of Ireland is situated in north-west Europe. The population is approximately 4.6 million people, with 13.0% of the population diagnosed with a disability, children under 1 year 1.0% in 2006 and 1.6% in 2011, children between 1–4 years 1.9% in 2006 and 3.1% in 2011, children of 5–9 years 4.2% in 2006 and 6.1% in 2011 (Central Statistics Office, 2012). There are no epidemiological studies in Ireland to estimate the prevalence of ASD. Ireland joined the European Union in 1973 and transformed the traditional agriculturally based economy into the largely technologically advanced “Celtic Tiger”. Religion is important for Irish people; the primary religion in Ireland is Roman Catholicism.

Ireland experienced immigration in the last 10 years when population from East European countries, Asia and Africa came to live and work here. Seward et al. (2005) have shown the transition of Irish families in the twentieth century from families characterized as being patriarchal, stem-extended, large, strong, and stable, to families that became more democratic, smaller, more independent and more diverse.

In Ireland, children with disabilities including autism spectrum disorder (ASD) traditionally lived at home and were largely “hidden” from public view in large family networks. Early efforts to achieve recognition of ASD as a separate category in education were made by the Irish Society for Autism that was formed in 1963. The drive for the treatment of health and education of children with ASD has developed over the past 10 years. Early intervention services have been created recently to support as early as possible children with ASD and their parents.

It is thought that in Ireland, an estimated one in 166 people, is or could be diagnosed with, an ASD, although international evidence suggests that incidence rates may actually be higher (Irish Times 2009).

The Report of the Task Force on Autism (2001) in the Republic of Ireland indicates that diagnosis of autistic disorder is on the increase. The figure below (Figure 5-1) from the Report of the Task Force for Autism, Irish Society for Autism and ERHA, 2001, shows the prevalence of individuals already diagnosed with autistic disorder in Ireland.

The Report of the Task Force on Autism (2001) estimates that the prevalence rate for ASD would be 20 per 10,000. An estimated number of persons with autistic disorder 0–19 years would be 2,398.

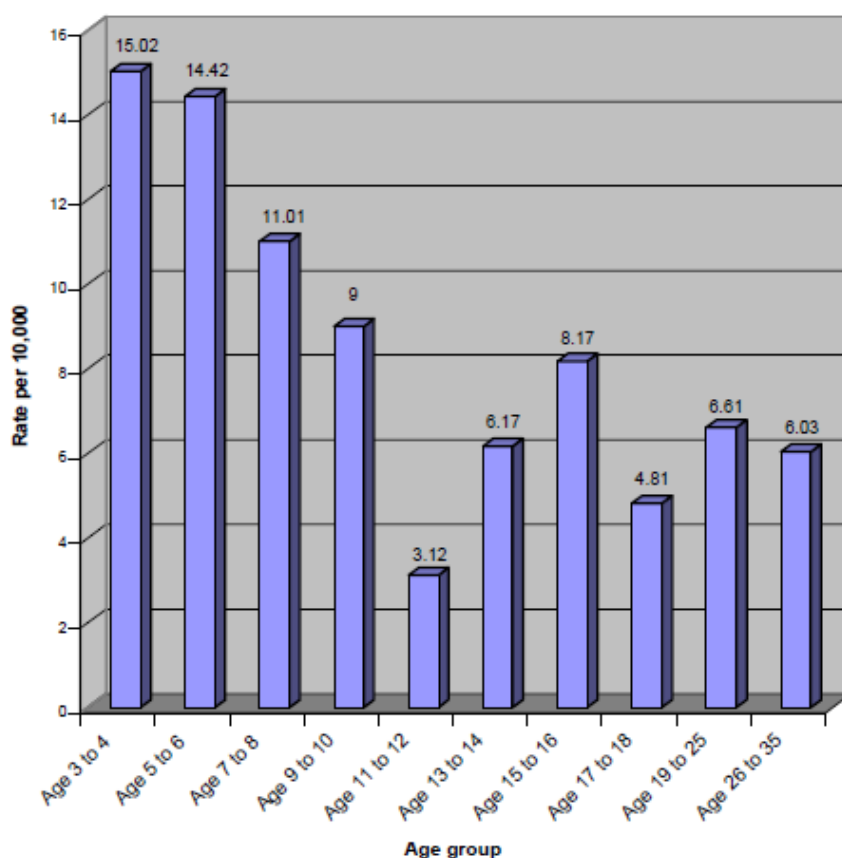


Figure 5-1 Prevalence of those diagnosed with autistic disorder (Irish Society for Autism and ERHA, 2001).

#### *Demographic aspects Ireland-Dublin West*

The description of demographic aspects was based on the Census of Population 2006 which took place in the Republic of Ireland in 2006. Dublin West has a number of

notable differences when compared to the State as a whole. In 2006, 2.2% of the Irish population lived in Dublin West. Dublin West had much higher population growth than the national average between 2002 and 2006. People in Dublin West are slightly less likely to be married than the national population (48.0% vs. 48.8%) and almost equally likely to be separated/divorced. The average age of the Dublin West population is 30.2 years. This is well below the national average of 35.6 years.

In the Census of Population 2006, 5,741 people in Dublin West indicated that they had a disability – or 6.2% of the population. This is lower than the national average of 9.3%. All age groups have disability rates below the national average. In terms of family cycle, the results shown that there are more families with pre-school age children than the national average (22.8% in Dublin West and 15.9% national average). These demographic aspects can be linked with the lower age profile of Dublin West residents who participated in this research. The chapter on data analysis - semi-structured interview results, describes in more detail the age of parents.

In Dublin West there are 11,902 families with at least one child under 15 years of age. This means that 39.4% of households have families with children under 15 years, compared to 31.4% of households nationally. In Dublin West, 32.5% of these families have one child, with 37.2% having two children, there are more families with at least one child under 15 years old, headed by a single mother; 22.4% compared to 19.7% nationally, people are more likely to have finished education past the age of 20 than the national average, 38% completed their education at age 17 or below compared to 50% of men in the State as a whole, and women are less likely to have finished their education aged 15 years or under (14% vs. 19%) than women in the rest of the State.

## 5.2. Legislative framework for children with autism

In Ireland, the Disability Act 2005 stipulates that children under five years of age have a right to an independent assessment of their health and educational needs. After assessment, families will receive an assessment of need report, specifying their child's health and educational needs and services required to meet those needs.

The assessment of need process started as part of the implementation of the Disability Act, 2005. Under the terms of the assessment of need process an assessment should be commenced within three months of referral. The Early Intervention Teams are usually involved in both assessment of need and intervention. A number of disciplines work individually for assessment and intervention. As a result, delays are often expected during the assessment of need process and intervention. However, there is lack of clarity and implementation of multidisciplinary approach in assessment and intervention.

The Citizens Information Board has a particular remit to help people with disabilities identify and understand their needs and options. The main payments to support children with ASD in Ireland are: Domiciliary care allowance, Carer's allowance and Carer's benefit, Incapacitated child tax credit, Tax relief on medical expenses, Home tuition grant, Respite grant.

### *Domiciliary care allowance*

Domiciliary care allowance is a monthly payment, paid by the Department of Social Protection (Up to 2009 it was paid by the Health Service Executive (HSE)). To qualify for this payment, a child must have a severe disability that is likely to last for at least one year. An annual respite care grant is automatically paid with the domiciliary care allowance.

### *Carer's allowance*

Carer's allowance is a means-tested payment for carers on low incomes who live with and look after people who need full-time care and attention. If a child qualifies for domiciliary allowance, then he/she qualifies for carer's allowance. If a child and the family qualify for carer's allowance, they also qualify for free household benefits (these include free electricity/gas, telephone rental allowances and a free television licence) and a free travel pass.

#### *Carer's benefit*

If parents wish to leave the work force for up to two years to care for their child, they may qualify for carer's benefit. This payment is based on pay-related social insurance (PRSI) contributions.

#### *Incapacitated child tax credit*

Parents can claim a tax credit of €3,660 if their child has a permanent disability. The disability must have arisen before the child reached the age of 21 or while she or he was in full-time education. The Revenue Commissioners regard cystic fibrosis, spina bifida, blindness, deafness, Down Syndrome, spastic paralysis, certain forms of schizophrenia and acute autism as permanent disabilities.

#### *Tax relief on medical expenses*

A tax refund at standard rate is available for money spent on certain medical expenses: doctor's visits, educational psychological assessments for a dependent child, hospital or nursing home costs, medication costs which have not been covered by the Drugs Payment Scheme, physiotherapy, speech and language therapy for a dependent child, and supply and repair of medical or surgical appliances used on medical advice.

#### *Home tuition for children with special educational needs*

Home tuition is provided as an interim provision only and should not be regarded as an optional alternative to a place in school. The purpose of the Home Tuition Scheme

is to provide a compensatory educational service for children who, for a number of reasons such as chronic illness, are unable to attend school. The scheme was extended in recent years to facilitate tuition for children awaiting a suitable educational placement and also to provide early educational intervention for pre-school children with autism.

Children with ASD and their families may also benefit from in-home *respite support* from *Family Support Services and Home Help Services* that may support them to manage their daily life and difficulties. These services are paid by the HSE and/or voluntary agencies. The above services are only temporary or additional supports. These supports may help families in raising a child with ASD but parents/caregivers remain the main carers for a child. It is acknowledged that the need for respite, home help and family support worker is higher for children with ASD.

The reconfiguration of services for children and young people in Ireland is in line with current programme for Progressing Disability Services for Children and Young People (0–18s). Different approaches to the delivery of services for children with ASD are evident across Local Health Office (LHO) areas and Service Areas (SA). Schools should be adapted to children with ASD and all, HSE, National Education Psychological Service (NEPS) and the Special Education Support Service (SESS) should offer a holistic approach to meet the educational needs for children with ASD.



### 5.3. Assessment and diagnosis

In Ireland there is no consistency about the assessment of ASD as the assessments are conducted in both public and private sectors. However, in 2011, the Psychological Society of Ireland (PSI) Special Interest Groups developed Best Practice Guidelines for the Assessment and Diagnosis of Autistic Spectrum Disorders for Children and Adolescents (birth to 18 years). The implementation of these guidelines are not clear in the assessment field of children with ASD. However, a multidisciplinary assessment should be conducted to diagnose children with ASD. The HSE, National Review of Autism Services Past, Present and Way Forward (2012) described the most used and useful ASD diagnostic instruments as follows (Table 5-1):

Table 5-1 ASD diagnostic instruments. The HSE, National Review of Autism Services Past, Present and Way Forward

Instruments	Advantages	Disadvantages
ADI	Reliable Good sensitivity and specificity Query stability when used under 4 years	3.5 hours Requires training Validated in 4-18 year olds Validity reduced in < 4-year- olds Informant based only and therefore subject to reporting biases.
DISCO	Reliable Good sensitivity and Specificity	3.5 hours Requires training Validated in 4-18 year olds Validity reduced in <4year old Informant based only and therefore subject to reporting biases
3-Di Computer based	Reliable Good sensitivity and specificity Screens for other co-morbid	2 hours + Requires training and software installation Informant based only and

	conditions , conduct disorders, ADHD and ADD consistent with DSM-IV Computer generated reports	therefore subject to reporting biases
CARS	Quick Includes observation section Quantitative score	Lower reliability
GARS	Quick to administer	Lower reliability
ADOS	30–45 minutes Various modules depending on language and development	Cannot be used in isolation May be too short to detect rigid and repetitive behaviours. May over classify PDD-NOS as autism due to reliance on social and communication domains. Observational and based on view of the child therefore more information is required

There are a few tests that can identify children aged 18 months who are at risk of having social-communication disorders. One of them is The Checklist for Autism in Toddlers (CHAT) (Baron-Cohen et al., 2000).

Many children with an ASD present with co-morbid psychiatric conditions. Therefore, these children are usually referred for assessment and intervention to the local Child and Adolescent Mental Health Services (CAMHS). In Ireland the diagnostic process takes on average 16 months to complete (Keenan et al., 2007). In some other countries such as Romania, the time scales for diagnosis are not described in the literature.

#### 5.4. Services available for children and families

The Irish Government funds the Irish health services to deliver services for the disability sector. Early intervention services are provided by statutory and non-governmental agencies. Carroll et al. (2013) suggest that there is a wide variation and no national consistency in service provision. Every region has its own referral criteria to the early intervention service. As a result, parents/caregivers may find it very stressful to access early intervention services for their child (Foran and Sweeney, 2010). There is currently no national policy for common early intervention services in Ireland.

Because of the inconsistency in service delivery and extremely long waiting lists, parents of children with ASD are often concerned about their child's ability to access services. As an example, during the data collection in Romania, one family who previously lived in Dublin for 13 years, returned to Romania to accessing early intervention services after their child's ASD diagnosis. Thus, services for children with ASD in Ireland are currently uncoordinated and poorly developed in many areas of the country. There is a crucial need to develop specialized services for children with ASD.

Both health and educational services should coordinate and develop for service improvements for children with ASD. The Progression of Early Intervention Disability Services in Ireland indicates that the "early intervention provision in Ireland is in a state of flux with an emphasis on developing national uniformity of family-centred early intervention services" (Carroll et al, 2013).

The Education for Persons with Special Educational Needs (EPSEN) Act (Government of Ireland, 2004) provides the legislative framework for the delivery of education for children with disabilities between 4 and 18 years of age. In Ireland, Public Health Nurses (PHNs) usually identify children who are at risk of having a delay/disability through regular checks. Then, children are referred for assessment and intervention to Primary Care Teams. For children who present with complex

needs, referrals are made to the local Early Intervention Service in Primary Care Services.

## 6. Assessment

Despite the new DSM5 diagnostic criteria for ASD, the diagnosis is still influenced by intellectual ability and co-morbid conditions. The assessment process for children with ASD indicates that clinical judgement and assessor experience are superior to the standard diagnostic tool used (such as ADI-R and/or the ADOS-G). However, both clinical judgement/experience and standard tools are probably the best combination for diagnosis of children with ASD. A complete assessment of ASD should include a medical history that needs to be evaluated by paediatric services.

Identifying early signs is probably the most important predictor in diagnosing ASD and implementing early intervention services. Guinchat et al. (2012) assessed parents' first concerns about their autistic child. Most parents express concerns during the first two years of life (De Giacomo and Fombonne, 1998).

Traditionally, the assessment process in most countries was child-focused, even though today professionals aim to consider the needs of parents and other family members. Assessment instruments differ internationally, although increasingly standardized assessment instruments are being used, as described below.

By using these kinds of assessment tools, detailed information from parents, grandparents, siblings, teachers, classmates, other professionals are used from different contexts, such as school, clinics, home or the playground.

## 6.1. Assessment tools

The main focus of this research is the diagnostic process of children with ASD and its implications. A description of selective tests that are internationally used for diagnosis is essential in understanding the process of diagnosis.

The Autism Diagnostic Observations Scale-Generic (ADOS-G) and The Autism Diagnostic Interview-Revised (ADI-R) are the main diagnostic standards. Other instruments are recognized and used internationally and described below. Researchers who have made significant contributions to the field since include amongst others *Asperger* (1944) (Asperger's Syndrome), *Rutter* (2000) (The Autism Diagnostic Observation Schedule-Generic, The Autism Diagnostic Interview, epidemiological studies), *Bailey* (1996) (genetic research in autism), *Frith* (2003) (theory of mind, neuropsychology of autism), *Schopler* (1990, 1988) (The Psychoeducational Profile Revised - PEP-R, The Childhood Autism Rating Scale-CARS), *Wing* (1997) (prevalence of autism), *Howlin* (1987) (diagnosis experience in autism, treatment and intervention), *Gilliam* (1995) (The Gilliam Autism Rating Scale), *Baron-Cohen* (1996) (The Checklist for Autism in Toddlers, theory of mind), *Lord* (1997, 2000) (The Autism Diagnostic Observations Scale-Generic - ADOS-G, The Autism Diagnostic Interview-Revised - ADI-R), *Leekam* (2002) (The Diagnostic Interview for Social and Communication Disorders - DISCO), *Siegel* (2004) (The Pervasive Developmental Screening Test-Stage 3), *Stone* (2000) (The Screening Tool for Autism in Two-Year Olds), and *Carter* (1998) (The Vineland Adaptive Behavior Scales).

### The Autism Diagnostic Observations Scale-Generic (ADOS-G)

The Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2002) is an instrument for diagnosing autism. It was created by Catherine Lord, Michael Rutter, Pamela C. DiLavore and Susan Risi, in 1989. The ADOS only became available in 2001 through the Western Psychological Services

The Autism Diagnostic Observation Schedule (ADOS) is a semi-structured assessment of communication, social interaction, and play (or imaginative use of materials) for individuals suspected of having an autism spectrum disorder. The ADOS consists of five modules, for children and adults of different developmental and language levels, from non-verbal to verbally-fluent.

The ADOS consists of standardized activities that allow the examiner to observe the occurrence or non-occurrence of behaviours that have been identified as important to the diagnosis of autism across developmental levels and chronological ages. The examiner selects the module that is most appropriate for a particular child or adult on the basis of his/her expressive language level and chronological age. Structured activities and materials, as well as less structured interactions, provide standardized contexts in which social, communicative and other behaviours relevant to pervasive developmental disorders are observed. Within each module, the participant's response to each activity is recorded. Overall ratings are made at the end of the schedule. These ratings can then be used to formulate a diagnosis through the use of a diagnostic algorithm for each module. The ADOS provides a 30– to 45–minute observation period during which the examiner presents the individual being assessed with numerous opportunities to exhibit behaviours of interest in the diagnosis of autism/PDD through standard “presses” for communication and social interaction. The modules provide social-communicative sequences that combine a series of unstructured and structured situations.

Module 1 is intended for individuals who do not consistently use phrase speech (defined as non-echoed, three-word utterances that sometimes involve a verb and that are spontaneous, meaningful word combinations). Materials for Module 1 have been selected for young children, but materials from other modules may be substituted if desired.

Module 2 is intended for individuals with some phrase speech who are not verbally fluent.

Module 3 is intended for verbally fluent children for whom playing with toys is age-appropriate (usually up to 12–16 years of age). Verbal fluency is broadly defined as having the expressive language of a

typical four-year-old child; producing a range of sentence types and grammatical forms, using language to provide information about events out of the context of the ADOS, and producing some logical connections within sentences (e.g. "but" or "though").

Module 4 includes the many of the tasks in Module 3 (some of which are optional), as well as additional interview items about daily living. It is intended for verbally-fluent adolescents and adults. The difference between Modules 3 and 4 lies primarily in whether information about social-communication is more appropriately acquired during play or a conversational interview.

The four modules overlap in activities, but together contain a variety of tasks ranging from observing how a young child requests that the examiner continue blowing up a balloon in Module 1 to a conversation about social relationships at school or work in Module 4. Modules 1 and 2 will often be conducted while moving among different places around a room, reflecting the interests and activity levels of young children or children with very limited language; Modules 3 and 4 take place sitting at a table and involve more conversation and language without a physical context.

The ADOS offers clinicians and researchers the opportunity to observe social behaviour and communication in standardized, well-documented contexts. These contexts are defined in terms of the degree to which the examiner's behaviour structures the individual participant's response and social initiative.

Its goal is to provide standardized contexts in which to observe the social-communicative behaviours of individuals across their life span in order to aid the diagnosis of autism. A strategy to measure absolute gains is to re-administer the same modules over time, as well as administering the developmentally-appropriate module.

In 2012, the Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2) has been released and is now used internationally. The ADOS-2 has some improvements, especially in Modules 1 and 4.



## The Autism Diagnostic Interview–Revised (ADI-R)

Autism Diagnostic Interview-Revised (ADI-R) (Le Couteur, 2003) was developed by Ann Le Couteur, Catherine Lord and Michael Rutter and published by Western Psychological Services in 2003.

The Autism Diagnostic Interview-Revised (ADI-R) is a clinical diagnostic instrument for assessing autism in children and adults. The ADI-R provides a diagnostic algorithm for autism as described in both the ICD-10 and DSM-IV. The instrument focuses on behaviour in three main areas: qualities of reciprocal social interaction; communication and language; and restricted and repetitive, stereotyped interests and behaviours. The ADI-R is appropriate for children and adults with mental ages from about 18 months and above.

The ADI-R is a standardized, semi-structured clinical review for caregivers of children and adults. The interview contains 93 items and focuses on behaviours in three content areas or domains: quality of social interaction (e.g. emotional sharing, offering and seeking comfort, social smiling and responding to other children); communication and language (e.g. stereotyped utterances, pronoun reversal, social usage of language); and repetitive, restricted and stereotyped interests and behaviour (e.g. unusual preoccupations, hand and finger mannerisms, unusual sensory interests). The measure includes other items, such as self-injury and overactivity. Responses are scored by the clinician based on the caregiver's description of the child's behaviour. Questions are organized around content area, and definitions of all behavioural items are provided. Within the area of communication, for example, "delay or total lack of language not compensated by gesture" is further broken down into specific behavioural items: pointing to express interest, conventional gestures, head nodding, and head shaking. Similarly, within the area of reciprocal social interaction, lack of socio-emotional reciprocity and modulation to context include the following behaviours: use of other's body, offering comfort, inappropriate facial expressions, quality of social overtures, and appropriateness of social response.

All of the questions ask about current behaviour, with the exception of a few behaviours that only occur during specific age periods. In these cases, specific age restrictions are given. The ADI-R interview generates scores in each of the three content areas (i.e. communication and language, social interaction, and restricted, repetitive behaviours). Higher scores indicate problematic behaviour in a particular area. Scores are based on the clinician's judgment following the caregiver's report of the child's behaviour and development. A classification of autism is given when scores in all three content areas of communication, social interaction, and patterns of behaviour meet or exceed the specified cut-offs, and onset of the disorder is evident by 36 months of age. The same algorithm is used for children from mental ages of 18 months through adulthood, with three versions containing minor modifications: 1) a life-time version; 2) a version based on current behaviour; and 3) a version for use with children under the age of 4 years.

Because the ADI-R is an interview rather than a test, and because it focuses on behaviours that are rare in non-affected individuals, it provides categorical results rather than scales or norms. Results can be used to support a diagnosis of autism or to determine the clinical needs of various groups in which a high rate of autism spectrum disorders might be expected (e.g., individuals with severe language impairments or certain medical conditions, children with congenital blindness, and children suffering from institutional deprivation).

The ADI-R has proven to be effective in differentiating autism from other developmental disorders and in assessing syndrome boundaries, identifying new subgroups, and quantifying autistic symptomatology. The extensive use of the ADI-R in research and clinical settings has provided strong evidence of reliability and validity.

#### Social Responsiveness Scale (SRS)

The Social Responsiveness Scale (SRS) (Constantino and Gruber, 2005) was developed by Constantino and Gruber and published by Western Psychological Services in 2003. The Social Responsiveness Scale (SRS) is a questionnaire that

contains dimensions of interpersonal behaviour, communication and repetitive/stereotypic behaviours that are characteristic of autism spectrum disorders. The SRS is a 65-item rating scale that measures the severity of autism spectrum symptoms as they occur in natural social settings. It includes one parent and one teacher forms.

SRS comprises 5 subscales: Social Awareness, Social Cognition, Social Communication, Social Motivation and Autistic Mannerisms. SRS offers a clear picture of a child's social impairments, assessing social awareness, social information processing, capacity for reciprocal social communication, social anxiety/avoidance, and autistic preoccupations and traits.

#### Social Communication Questionnaire (SCQ)

The Social Communication Questionnaire (SCQ) (Rutter et al., 2003) was developed by Rutter, Bailey and Lord. It was previously known as the Autism Screening Questionnaire (ASQ), and published by Western Psychological Services in 2003. It was initially designed as an additional screening measure for the Autism Diagnostic Interview-Revised (ADI-R).

The SCQ is a parent/caregiver dimensional measure of ASD symptomatology appropriate for children of any chronological age older than four years. It can be completed by the informant in less than 10 minutes. The SCQ is available in two forms, Lifetime and Current, each with 40 questions presented in a 'yes or no' format. Scores on the questionnaire provide an index of symptom severity and indicate the likelihood that a child has an ASD. Questions include items in the reciprocal social interaction domain, the communication domain and the restricted, repetitive, and stereotyped patterns of behaviour domain.

Compared to other screening measures, the SCQ demonstrated its effectiveness in predicting ASD versus non-ASD. The SCQ is one of the most used ASD evaluation tools and can be utilized for screening and as part of comprehensive developmental assessment for ASD (Norris and Lecavalier, 2010; Wilkinson, 2010). SCQ is brief,

easily administered and relatively inexpensive; it allows clinicians and educators to routinely screen children for autism spectrum disorders. The SCQ is suitable for screening and monitoring.

#### Gilliam Autism Rating Scale (GARS)

The Gilliam Autism Rating Scale, GARS–2 is a revision of the widely used *Gilliam Autism Rating Scale* (1995). The GARS–2 was developed by Gilliam (2006). It was designed to assist psychologists, teachers, parents, and clinicians in identifying and diagnosing autism in individuals from age 3 to 22 and is assessing the severity of the disorder.

The GARS-2 can be individually administered in 5 to 10 minutes and consists of 42 items describing the characteristic behaviours of persons with autism. The items are grouped into three subscales based on two definitions of autism: Stereotyped Behaviours, Communication, and Social Interaction.

According to the manual, the GARS-2 should be administered by professionals who have training and experience in working with individuals with autism such as school psychologists, educational diagnosticians, and autism specialists. Although the GARS-2 may have value as a screening tool for ASD, it is not recommended to be used as the main instrument in a comprehensive developmental assessment battery for autism (Norris and Lecavalier, 2010).

#### The Childhood Autism Rating Scale (CARS)

Childhood Autism Rating Scale (CARS) was developed by Schopler, Reichler and Renner. CARS is a behavioural scale that helps to identify children 2 years and older with autism. In addition, it distinguishes between mild-to-moderate and severe autism. The CARS2 helps to integrate diagnostic information, determine functional capabilities, provide feedback to parents, and design targeted intervention (Schopler et al., 1998). The areas covered by the CARS2-QPC include the individual's early

development; social, emotional, and communication skills; repetitive behaviours; play and routines; and unusual sensory interests.

Standard Version Rating Booklet (CARS2-ST) is for use with individuals younger than 6 years of age and those with communication difficulties or below-average IQs. High-Functioning Version Rating Booklet (CARS2-HF) is used for assessing verbally fluent individuals, 6 years of age and older, with IQ scores above 80. Questionnaire for Parents/Caregivers (CARS2-QPC) collects information for use in making CARS2-ST and CARS2-HF ratings.

The CARS2-ST and CARS2-HF each include 15 items: Relating to People, Imitation (ST); Social-Emotional Understanding (HF), Emotional Response (ST); Emotional Expression and Regulation of Emotions (HF), Body Use, Object Use (ST); Object Use in Play (HF), Adaptation to Change (ST); Adaptation to Change/Restricted Interests (HF), Visual Response, Listening Response, Taste, Smell, and Touch Response and Use, Fear or Nervousness (ST); Fear or Anxiety (HF), Verbal Communication, Non-verbal Communication, Activity Level (ST); Thinking/Cognitive Integration Skills (HF), Level and Consistency of Intellectual Response, General Impressions.

The Checklist for Autism in Toddlers (Baron-Cohen et al., 1996)

The Checklist for Autism in Toddlers (CHAT) was developed by Baron-Cohen and colleagues (Baron-Cohen et al., 2000). It is a screening instrument which identifies children aged 18 months who are at risk of having social-communication disorders.

It consists of a short questionnaire which is filled out by the parents and a primary health care worker at the 18 month developmental check-up. CHAT contains two sections: the first nine items are questions asked to the parents, and the last five items are observations made by the primary health care worker. If some behaviours are absent at 18 months, a child can be classified at risk for a social-communication disorder. These behaviours are (a) joint attention, including pointing to show and gaze-monitoring, and (b) pretend play.

The CHAT comprises five key items: pretend play, pointing, following a point, pretending and producing a point. If a child fails all five key items, they have a high risk of developing autism. Children who fail two specific items have a medium risk of developing autism.

A child who fails the CHAT should be rescreened approximately one month later. A child who fails the CHAT for a second time should be referred to a specialist service for diagnosis.

### Psycho-educational Profile-Revised (PEP-R)

The Psycho-educational Profile-Revised (PEP-R) (Schopler, Reichler, Bashford, Lansing, & Marcus, 1990) is a developmental approach to the assessment of children with autism. The Psycho-educational Profile-Revised (PEP-R) is an inventory of behaviours and skills designed to identify learning patterns. The test is used for children from six months to seven years. The PEP-R provides information on developmental functioning in imitation, perception, fine motor, gross motor, eye-hand integration, cognitive performance, and cognitive verbal areas.

The PEP-R provides information about behavioural abnormality, play and interest in materials, sensory responses, and language. The PEP-R kit consists of a set of toys and learning materials that are used by clinicians within structured play activities. There are 131 developmental and 43 behavioural items on the PEP-R.

The total time required to administer and score these items is from 45 minutes to 1.5 hours. The scores are distributed among seven developmental and four behavioural areas. The resulting profiles show a child's strengths and weaknesses in different areas of development and behaviours.

The Developmental Scale measures child's functioning in comparison to peers. The items on the Behavioural Scale can classify behaviours consistent with a diagnosis of autism.

Vineland Adaptive Behavior Scales, Second Edition (Vineland-II) (Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005)

The Vineland Adaptive Behavior Scales (VABS) were developed by Carter, Sparrow, Balla, & Cicchetti (1998)

The Vineland II include the following forms: Survey Interview Form, Expanded Interview Form, and Parent/Caregiver Rating Form; Teacher Rating Form. The Vineland is designed to measure adaptive behaviour of individuals from birth to age 90. The Vineland II Survey forms are used in the clinical diagnosis of a variety of disorders, including autism spectrum disorders.

The survey Interview and Parent/Caregiver Rating Forms take approximately 20–60 minutes to complete. The expanded Interview takes 25–90 minutes to complete and the Teacher Rating Form takes only 20 minutes.

The Vineland-II contains 5 domains each with 2–3 subdomains. The main domains are: Communication, Daily Living Skills, Socialization, Motor Skills, and Maladaptive Behaviour (optional). The two survey forms, the Survey Interview Form and the Parent/Caregiver Rating Form, assess adaptive behaviour in the four domains of Communication, Daily Living Skills, Socialization and Motor Skills, and include a Maladaptive Behaviour Domain that assesses problem behaviours.

With the Survey Interview Form and the Parent/Caregiver Rating Form, the Vineland-II can provide an assessment of the individual's current level of functioning.

Wechsler Preschool and Primary Scale of Intelligence Rev. ed. (WPPSI- R)

There are a few tests that measure children's cognitive aspects. A very useful tool for the measurements of children's intelligence is Wechsler Preschool and Primary Scale of Intelligence (Rev. ed.) (WPPSI- R) (Wechsler, 1989).

WPPSI-R is widely used as a standardized test of intelligence for children with ASD. The Wechsler Preschool and Primary Scale of Intelligence (Rev. ed.) (WPPSI- R)

(Wechsler, 1989) is an intelligence test for children from three to seven years of age. The WPPSI-R contains 11 subtests and a performance subtest, Object Assembly. The WPPSI-R is widely used as the best standardized measure of intelligence.

The above tests, the results and its implications are usually discussed with parents/caregivers or should be discussed with them. The diagnosis process and its implications is largely discussed in Chapter 7.



## 7. Diagnosis process

### 7.1. Diagnosis and prevalence

In terms of ASD prevalence in Europe and worldwide, the research shows that the prevalence of autism spectrum disorders (ASD) in children has risen in European countries and around the world over the past decades. The prevalence of ASD across countries is different. Williams et al. (2006) found that the age of children when diagnosed, country of origin, urban/rural areas, the diagnostic criteria used, have all influenced the ASD rates. Fombonne (2009) suggests that the best estimates based on recent surveys for ASD is 60 to 70 per 10,000.

Centers for Disease Control (2009) estimated that 1% of the general population has ASD (1 in 110 children).

Samadi et al. (2012) reported that from 2006 to 2009 a national screening programme which examined the prevalence of autism among five-year-old children in Iran, and using the Autism Diagnostic Interview-Revised (ADI-R), found the ASD prevalence of 6.26 per 10,000 for typical autism, which is in line with rates for certain countries but is lower than those reported recently for some Western nations. This study concluded that this may be due to the younger age range assessed, but the suitability of the tools and aspects of Iranian culture could be other reasons for the lower prevalence. Thus, further research is needed on cultural influences on parental perceptions of children's difficulties, and screening/assessment tools should be adapted to ensure comparability with procedures used in other countries. According to these authors, in Iran, the prevalence of children assessed as having ASD was twice as high in the more developed provinces (8.81 per 10,000) than in the less-developed provinces (3.88 per 10,000).

A review of the prevalence of Autism Spectrum Disorder in Asia (six countries) from 1971 to 2008, suggests that the ASD is probably more common in Asia than previously thought (Sun et al., 2010). The average prevalence of ASD in Asia before 1980 was around 1.9/10,000 while it was 14.8/10,000 from 1980 to 2008. This study

shows the prevalence after 1980, which suggests that after adopting DSM-III/IV or ICD-10 as the diagnostic criteria, the prevalence of ASD increased dramatically in Japan, but decreased in China. The median prevalence was 15.5/10,000 in Japan and 10.4/10,000 in China.

Hsu et al. (2012) conducted a cross-sectional study to describe the prevalence of ASD in Taiwan, exploring the effects of age, gender, and urbanization on ASD occurrence. The prevalence was found 12.3% (10,868/884,771) in the general population and the prevalence among males (19.2%) was significantly higher than among females (6%). The metropolitan areas had a higher prevalence of autistic cases than the rural areas in Taiwan.

In the UK, Baron-Cohen et al. (2009) found the prevalence of ASD to be 157 per 10,000. In Australia, from 2003 to 2004, MacDermot et al. (2008) reported ASD rates for 6–12 years olds to be 9.6–40.8 per 10,000. Eapen et al. (2007) examined 694 three-year olds in the United Arab Emirates and found 58 children per 10,000 with autistic features. High rates were reported by Nicholas et al. (2009) who evaluated 47,726 children (9 years old) in South Carolina (USA). These authors reported a prevalence rate of 62 per 10,000.

In the USA, Kogan et al. (2007) found that about one in one in 110 school-age children is diagnosed with autism spectrum disorder (ASD).

Matson and Kozlowski (2011) reviewed the literature and research in ASD prevalence and concluded that the number of cases has risen enormously. Among the most common possibilities, they described the expanded diagnostic criteria, more awareness of the disorder, diagnosis at earlier ages, and the recognition of ASD as a lifelong condition.

Worley et al. (2011) used a sample of toddlers at risk for, or currently diagnosed with, a developmental delay to determine the prevalence rate. The results underline that the prevalence rates of ASD were greater in this ‘at risk’ sample of toddlers compared to rates reported in community or clinical samples. These authors concluded that the results highlight the need for “routinely assess toddlers for the

presence of symptoms of ASD who are already receiving early intervention services for other developmental delays” (p.920)

The number of children diagnosed with one of the ASDs is increasing each year and epidemiological studies across time suggest that rates have risen dramatically from the original estimate 40 years ago of 4 per 10,000 (Dover and LeCourter, 2007) to somewhere in the region of 30 to 60 cases per 10,000 (Rutter, 2004). Some studies report even higher rates of 100–116 cases per 10,000 children diagnosed with ASDs (Baird et al., 2006; NAS, 2006) that indicate a possible epidemic of autism (Fombonne, 2001, 2003). Lordi and Silverberg (1964) found that “the syndrome of autism in young children is being reported with increasing frequency, but whether this is due to a growing incidence or to increased awareness of the phenomena is as yet not clear” (p. 360).

Yet, despite the fact that ASD can be diagnosed from around 2 years of age (Charman and Baird, 2002) and major progress has been made in the identification of ASD in children under the age of 2 years (Baron-Cohen et al., 1996), many families have to wait for months, or even years, in order to obtain a final diagnosis. Muhle et al. (2004) suggest that the increase in prevalence could be linked with more awareness and changes in diagnostic criteria rather than other factors. However, current levels of awareness of ASD and the diagnostic criteria could be considered as essential keys in diagnosing children at a very early stage. Further research should be conducted to clarify the increase number of children with ASD around the world.

## 7.2. Diagnosis stages and their implications

According with Mansell and Morris (2004) the process of diagnosis involves at least four stages during which families experience a range of emotions: pre-diagnosis, diagnosis, post-diagnosis, and a final stage of acceptance and adaptation.

In the *pre-diagnosis stage* the family commonly goes through a ‘suspicion’ phase, where they suspect that something is not the same with this child when compared to other typically developing children. Usually, they start searching for information (e.g. books, Internet, and friends). This can go on for months or even years and parents and other relatives may disagree about whether or not there is something to worry about. Oftentimes, during this phase, parents are told that their child is simply a “late developer” and “will grow out of it” (Byrne and Byrne, 2005). When parents finally decide to seek help, they usually consult their general practitioner in the first place. At this point, they may be told again not to worry and that their child is just slow in developing, or they may be referred for a full assessment and diagnosis.

The *diagnosis stage* includes a range of different professionals, including medical professionals, child psychiatrists, neurologists, psychologists, social workers, speech and language pathologists, occupational therapists, and others. Diagnosis may involve physical examination, neurological examination, a hearing test, learning disorders testing, psychological and neuropsychological testing, and extensive parent interviews. Agreement between the team is usually necessary before a diagnosis is made. This means that commonly, parents have to take their child to a number of different hospitals or assessment centres, although there are efforts to centralise diagnosis through designated assessment centres.

Reid (1999) from The Tavistock Clinic, London, identified 14 phases in the process of assessment; Phase 1: referral, Phase 2: observation, Phase 3: sharing observations and learning the child’s history, Phase 4: contact with other professionals, Phase 5: containment of possible family trauma, Phase 6: consultation, Phase 7: diary, Phase 8: family history, Phase 9a: assessment of child, Phase 9b: assessment of parents’ need, Phase 9c: assessment of siblings’ needs, Phase 10: review of impact of

assessment process on child and family, Phase 11: feedback, Phase 12: network communication, Phase 13: treatment plan for whoever in family is in need, Phase 14: ongoing assessment.

Finally, in the *post-diagnosis stage*, family members, including the extended family, experience many changes which mainly concentrate on the search for suitable interventions. Ideally, families are referred to appropriate services, aimed at the child and at supporting the family. Unfortunately, however, families are not always fully included in the diagnosis process, especially post-diagnosis when the family should be viewed as a real resource and should be engaged as co-therapists (Matson et al., 2009; Munteanu, 2009).

Eventually, parents may find a level of *acceptance and adaptation* where they learn to live with the reality of having a child with autism; they accept the diagnosis, but usually continue the searching for effective treatments and interventions until they are satisfied that they have got the best available service for their child (Byrne and Byrne, 2005).

The process of obtaining a diagnosis of ASD and subsequently delays in obtaining a diagnosis has often been described as stressful for parents (i.e. Siklos and Kerns, 2007; Wiggins et al., 2006; Mansell and Morris, 2004; Howlin and Moore, 1997)

During the diagnosis and feedback process, powerful feelings are experienced by parents. A number of studies have investigated family reactions during the diagnosis process (Twyman et al., 2009; Osborne et al., 2008; Stuart and McGrew, 2009; Watchtel and Carter, 2008; Mansell and Morris, 2004; Nissenbaum et al., 2002; Howlin et al., 1999; Midence and O'Neill, 1999). Professionals working with parents during the diagnosis process often do not take full account of the family structure, family members' roles, the support network, subsystems, and the extended family. At times, siblings and grandparents are not included in the assessment and treatment of their sister/brother/grandchild diagnosed with ASD and their unique needs are often not sufficiently considered.

Communicating the diagnosis of autism to parents may lead to parental satisfaction with the diagnostic experience (Osborne, 2008; Brogan and Knussen, 2003; Nissenbaum et al., 2002).

Nissenbaum et al., (2002) recommended nine guidelines to professionals involved in sharing a diagnosis of ASD with families: become knowledgeable about autism; establish a family-friendly setting; understand the family's needs; use good communication skills; provide a list of resources and interventions; provide follow-up; discuss prognosis; provide hope; recognize that it is not unusual for professionals to react to giving a diagnosis of autism.

### 7.3. ASD Diagnosis and support

The need for formal and informal support during the diagnostic process of ASD and thereafter is well recognized. This section explores some forms of supports that are considered beneficial to parents of children with ASD.

De Alba and Bodfish (2011) found in their study that parents received little help following ASD diagnosis. Studies have demonstrated that informal support from friends can reduce parental stress. Support from other mothers is a valuable resource (Dunst et al., 2007; Singh et al., 2007).

Benson and Karlof (2009) found that informal social support is related to decreased parent depressed mood over time. Support that provides parents with practical help (e.g. childcare, finances and housekeeping) may reduce the impact of stressors on parents. Studies have shown that informal supports can be very helpful (Singh et al., 2007; Thompson and Lobb, 1997) in terms of reducing parents' stress. Bristol (1984) suggested that family support is associated with lower levels of parental stress. For example, Singh et al. (2007) found that mindfulness increased parental satisfaction and conducted to more social interactions between parents and children, and showed low levels of parenting stress.

Families have a range of needs relating to caring for their child with ASD. They may need additional support in the house (home support services), time for themselves as a couple or as a family (respite services), information in managing their child's needs (parenting training) and they may need support from other parents in terms of sharing similar experiences and supporting each other (support groups).

Support and guidance during and after the diagnosis process is often missing. In Ireland, Keenan et al. (2007) found that 99% of the parents and professionals agreed that better support for parents is needed after diagnosis. Osborne and Reed (2008) suggested that parents need more support and better communication with professionals during the diagnosis process.

### *Information and training*

The diagnostic process of ASD is difficult and stressful for parents and the lack of information often creates additional stress for parents/caregivers. The need for information is frequently reported by families rather than other needs (Bailey and Powell, 2005). Based on literature review and clinical experience, as Social Worker for the Early Intervention Services in Dublin West, I developed a support group for parents in 2009. The pre- and post-group analyses indicated that most of the parents expressed a need for information and training.

Following diagnosis, parents need information about ASD and they need to develop strategies to respond to their child's specific needs. The National Autistic Society (NAS) in the UK has developed an autism-specific three-month parent package, (the NAS Early Bird Programme) to support parents of children with ASD. Shields (2001, p. 49, 55) indicates that parents who attended the Early Bird Programme have learned "to understand autism, to build social communication, and to analyse and use structure, so as to prevent inappropriate behaviours" The feedback from parents who have participated in the NAS EarlyBird Programme across the UK, shows that "the Early Bird way of working with parents is effective, empowering and much appreciated by families"

Some parenting programs, such as the Hanen Parent Programmes *More Than Words* (Sussman, 1999) and *The Incredible Years* (Sutton et al. 2004), should be accessible for all parents who need support. Training programs for parents of children with autism spectrum disorders demonstrate positive effects for both parent and child outcomes in terms of increasing parent skills and child language and communication outcome (Patterson et al., 2012).

Supports for parents, siblings, grandparents can include training programs, e-mail groups, family therapy, counselling and support groups. Above all, effective intervention based on scientific principles (i.e. applied behaviour analysis [ABA]) is viewed as the most important factors in promoting good family functioning, alleviating stress, and plays an important role in a family's capacity to facilitate the child's development and their ability to function as a family (Keenan et al., 2007)



As mentioned above, based on the literature review and clinical experience, as Social Worker for the Early Intervention Services in Dublin West, I developed a support group for parents in 2009. The pre- and post-group analyses also indicated that the most ‘wanted’ information for parents is access to services and types of services suitable to their child. Nevertheless, parents should be firstly informed about ASD. The team/person responsible for informing the parents about their child’s diagnosis have a crucial role in sharing information.

### *Support groups*

Several studies have demonstrated the positive impact of parent support between families of children with ASD, in the context of support groups (Mandell and Salzer, 2007; Luther et al., 2005).

Sharing experience and information could be beneficial for parents of children with ASD. However, not all parents are prepared to participate, or they do not have access to such a group. Parents of children with ASD could benefit from this ‘informal’ support in group in order to improve their understanding of their child’s needs and difficulties. Parents would also know where to seek support if needed. Sharing information is another aspect that support groups might find beneficial. It is not easy for parents to discuss their difficulties in front of a group.

### *Psychotherapy/Family therapy*

Psychotherapy (family therapy) is often recommended for children with ASD and their families (e.g. Ramisch, 2012). Starting with the diagnostic process, families may need additional support from professionals in order to help them cope with the impact of having a child with ASD, and its implications. A rationale for including family therapy in early intervention for children with disabilities, and the potential impact on the family system was outlined as being vital by Malone et al. (1997). Home-based family therapy is also considered beneficial (Cottrell, 1994) for families who have difficulties attending clinics. As various professionals who provide assessment and support on a home-based approach (GP, public/community nurses, social workers, ABA tutors etc.), family therapists are trained to offer this

intervention. Therefore, home-based and clinic-based family therapy offers support to families with children on the autism spectrum disorder which help them achieve strategies for managing family stress factors. Unfortunately, there is no research on the outcome of family therapy for parents of children with autism. This is an area that requires vigorous research.

Ramisch (2012) recommended the use of McCubbin and Patterson's (1983a) Double ABCX Model of adjustment and adaptation in family therapy with families of children with autism. This model can explore the following areas in a family therapy session: the pile-up of stressors and demands (obtaining a correct diagnosis, problem behaviours, financial hardship, unpredictability about the future, negative reactions of family members and society); and the resources, coping and adaptation. Ramisch (2012) recommended that therapists should focus on assessment and intervention for stressors, assessment and intervention for resources, assessment and intervention for coping and implications for research and training. Therapists should help parents to identify stressors that are contributing to the family system. Communication is vital for the therapeutic process. Secondly, therapists and parents can work together to acquire resources. After discussing stressors and resources, therapists should focus on parents' coping skills, such as: learning empathy and patience with their partner, maintaining the sense of self, solving problems and managing their family. Finally, there is a need for research about families who attend therapy.

Ramisch mentioned that "The ABCX model is a tool that therapists can use to help sort out the stressors, resources and coping skills of any particular family and evaluate the best place to intervene" (p. 314). The ABCX model is a tool that can help family achieve better adaptation.

Prior to the 1960s, child psychiatrists did not routinely include family members in child psychotherapy. In fact, it was Lordi and Silberberg (1964) who started to work with parents of children diagnosed with ASD in group therapy and emphasized the importance of involving parents in the diagnosis and treatment of their children.

#### *Early intervention services*

Accessing early intervention services is not often available to all children with autism and their parents for various reasons such as: the child's age when diagnosed, waiting lists, services available etc. Clearly, diagnosis should be followed by appropriate early intervention. Both children and parents need immediate access to Early Intervention Services. Staff working in Early Intervention for children with ASD and their families need a specific understanding of ASD and its implications. A holistic approach to diagnosis and intervention is the essential goal in ASD.

Unfortunately, the main focus in early intervention in ASD remains child-focused with some parent-focused and home-based approaches. Usually, the intervention for children with ASD is clinic-based. Literature suggest that early intervention programs between 18 months and 4 years of age are beneficial for children with autism and are likely to have the greatest positive impact (Veness et al., 2011; Rogers and Vismara, 2008)

## 8. Methodology

### 8.1. Aim of thesis

Few studies have examined family functioning and experience during the diagnosis process; none have offered a direct comparison of these issues between two countries. Therefore the main contribution of this research is to offer an insight into family systems variables, structural and functional characteristics of families during this process within a European comparative context.

The analysis of the similarities and differences of how families that are raising a child with autism function during the diagnostic process was expected to lead to better understanding of the overall experience of families and thus improve sensitivity during the diagnostic process.

This research took a family system perspective, exploring how families with children on the autism spectrum function during the particularly stressful period of the diagnosis process, and thereafter.

The main aim of the study is to provide an overview of the autism diagnostic within a cultural context and is based on a cross-cultural fixed comparative method research design.

## 8.2.Objectives of thesis

The objectives of this research were:

To explore the experience of diagnosis of ASD from the perspective of parents; and to compare the experience of diagnosis in two European cultures (Ireland and Romania);

To determine family functioning, i.e., family communication, cohesion, flexibility, satisfaction in families with children recently diagnosed with ASD; and to compare functioning in recently diagnosed families in two European cultures (Ireland and Romania)

To explore accessibility to treatment/service options for families whose child(ren) have recently been diagnosed with ASD; and to compare treatment/service options in two European cultures (Ireland and Romania)

The term *family functioning* in this study includes questions on how families adapt, the cohesion and flexibility of the family, family communication, the relationship between family subsystems, the family structure and allocation of family roles that were assessed with Family Adaptability and Cohesion Evaluation Scale IV (FACES IV) and a semi-structured interview, and treatment options available to children and their families. Particular emphasis was put on ‘subsystem function’ of parental and sibling subsystems as well as extended family subsystems.

### 8.3. Main research questions

- Are there any differences and/or similarities between aspects of family functioning in Irish and Romanian families of children with ASD during the diagnosis process?
- What is the experience of parents during the diagnostic process of their child/ren in Ireland and Romania?
- What is the parents' view in accessing diagnostic and post-diagnostic services for their children in Ireland and in Romania?
- Is the age of child's diagnosis with ASD and duration of diagnosis in Ireland different than in Romania?

#### 8.4. Hypotheses and null hypotheses

1. Aspects of family functioning (cohesion, flexibility, communication and satisfaction) in Irish families are different than aspects of family functioning in Romanian families

*There is no difference between aspects of family functioning in Romanian and Irish families.*

2. Main family worries regarding their child when received diagnosis in Ireland are different than family worries regarding their child when received diagnosis in Romania.

*There is no difference between Romanian and Irish families in terms of family worries.*

3. Irish families show level of involvement in their child's development differently than Romanian families.

*There is no difference between Romanian and Irish families in terms of their level of involvement in their child's development.*

4. Irish families have a different perspective regarding the role of the mother/father in raising a child with ASD than Romanian families

*There is no difference between Romanian and Irish families regarding the role of the mother/father in raising a child with ASD.*

5. The experience of a family regarding their child when received diagnosis in Ireland is different than the experience of a family regarding their child when received diagnosis in Romania.

*There is no difference between Romanian and Irish families in terms of their experience when receiving a diagnosis of ASD in their child.*

6. The age of children when diagnosed with ASD and duration of diagnosis in Ireland is different than the age of children when diagnosed with ASD and duration of diagnosis in Romania.

*There is no difference between Romanian and Irish children at age of diagnosis and the length of time to get the diagnosis.*

Balluerka1 et al. (2005) concluded that:

null hypothesis significance testing (NHST) is one of the most widely used methods for testing hypotheses in psychological research. It is concluded that rigorous research activity requires use of NHST in the appropriate context. (p. 55).

According to these authors in this research the null hypothesis significance testing was used.



## 8.5. Sample

Fifty-four families and their children were recruited from two institutions: 24 families from Ireland (Dublin, Cherry Orchard Hospital) and 30 families from Romania (Timisoara, Casa Faenza).

*Inclusion criteria* for families was that:

- they have at least one child between 2 and 7 years diagnosed with ASD according to ICD 10 F84.0 and DCM IV 299.00 criteria;
- they were through the diagnostic process at one of the participating institutions;
- no more than 12 months have passed since completion of diagnosis

In both countries, the diagnosis of autistic disorder was based on DSM-IV criteria for autistic disorder and made by board-certified child psychiatrists and clinical psychologists.

*Exclusion criteria:*

In this study, only ethnic Irish and Romanian families (no other ethnic backgrounds) were recruited to participate. Non-Irish/non-Romanian families were not included with the purpose of having a clear picture of the cultural family role in experiencing the diagnosis of ASD of their child.

Irish families and their children who participated in this study lived in the same geographic area in Dublin West and were evaluated using the same measures. Identically, Romanian families and their children who participated in this study lived in the same geographic area in Timisoara and were evaluated using the same measures.

## 8.6. Research design

This study is based on a cross-cultural fixed comparative method research design. Initially, the research design was established for mixed methods research. The mixed methods research is undertaken in many fields, such as education, psychology and social sciences. Hall and Howard (2008) suggested that “mixed methods approaches allow researchers to quantify and explore people’s lives” (p. 267). Furthermore, Murray (2003) recommended to blend qualitative and quantitative research methods in theses and dissertations. Based on difficulties experienced with the data collection (see data collection section), the decision was taken for comparative design.

Cross-cultural comparisons are essential to identify general characteristics. In the present study, parents’ experience of their children’s ASD diagnostic may identify universal experience during the diagnostic process. A profile of parents’ experience is needed for a better understanding of autism and its implications.

Norbury and Sparks (2013) stated that “there is little doubt that conditions such as SLI and ASD are universal, biologically influenced, and cross country and cultural boundaries” (p. 54). They questioned whether what we see is a difference or a disorder. Researchers and clinician should be vigilant of the cultural environment of children with autism and their families. It is important to understand autism in its context.

Comparing clinical samples from different countries presents a difficult challenge. First of all, the design of the study presented a very difficult challenge for the researcher as she lived and worked in both countries and impartiality constituted the challenge. Secondly, each country presents local and national characteristics that cannot be generalized. It is not clear to what extent parents’ experience reflect cultural aspects of each country (Ireland and Romania) and more importantly, their experience during the diagnostic process of their child.

Cultural variability can be interpreted dually in the present research study as a limitation and as a valuable contribution, due to its complexity and challenges.

The importance of cross-cultural comparative studies is largely emphasized in the literature (Freeth et al., 2013; Norbury and Sparks, 2013; Chung et al., 2012; Matson et al., 2011; Daley, 2002)

Chung et al. (2012) examined cross-cultural differences in challenging behaviours of children with autism spectrum disorders between Israel, South Korea, the United Kingdom and the United States of America. They used identical assessments across countries to collect data for comparisons. Findings found a:

few differences between the United States and both South Korea and Israel, with the United States endorsing a higher presence and severity on items that differed. In contrast, the United States and the United Kingdom differed on nearly half of the behaviour items assessed with the United Kingdom reporting greater endorsements. (p. 881).

Another contribution to cross cultural comparative studies is a cross-cultural comparison of autistic traits in the UK, India and Malaysia, conducted by Freeth et al. (2013). They compared the expression of autistic traits in a sample of neurotypical individuals from one Western culture (UK) and two Eastern cultures (India and Malaysia), using the Autism-spectrum Quotient (AQ) in order to identify possible cultural differences in the expression of autistic traits. They found that behaviours associated with autistic traits were reported to a greater extent in the Eastern cultures than in the Western cultures.

Matson et al. (2011) examined the cross- cultural differences in reported symptoms of autism spectrum disorders in Israel, South Korea, the United Kingdom, and the United States of America. They found differences in non-verbal communication/socialization, verbal communication and restricted interests and no significant differences in social relationships. Their study suggested that “certain behaviours that may be early markers of ASD in one culture/country may simply not be viewed as abnormal by parents in other cultures/countries” (p. 1601).

Comparison study relating to autism prevalence was conducted by Parner et al., (2011). They found that ASD prevalence rates were higher in Denmark (68.5 per 10,000 children) compared with Western Australia (51.0 per 10,000 children). Parner et al. (2011) concluded that:

In Denmark, assessments and services are all free of charge to families. In Western Australian assessments performed by non-government agencies have to be financed by families, and therefore many families opt for a government-subsidised assessment despite the longer waiting times, resulting in a delay in diagnosis. Therefore, the pathways operating in Western Australia may be promoting diagnostic bias in the population, whereby families of a lower socioeconomic status may be more likely to be referred at an older age, be at risk of receiving an alternate diagnosis and wait longer to receive a diagnosis through the government system. (p. 1606).

Dyches et al. (2004) examined multicultural issues in autism and suggested that some cultures are not willing to assess their child for any type of disability. They also found that students with multicultural backgrounds and autism are challenged on at least four dimensions: communication, social skills, behavioural repertoires and culture.

## 8.7. Instruments

A number of validated tests and instruments were considered to ensure that those used in the study are applicable for both Irish families and Romanian families. The instruments used include: Family Adaptability and Cohesion Evaluation Scales IV (FACES IV) and semi-structured interview. These two instruments were selected in order to emphasize family aspects during the diagnosis of autism.

### 8.7.1 Family Adaptability and Cohesion Evaluation Scale IV (FACES IV)

*Family Adaptability and Cohesion Evaluation Scale IV (FACES IV)* (Appendix 6) is a measure of family functioning (communication styles, family interactions, and flexibility) and contains three scales: cohesion, adaptability, and social desirability (Sholevar, 2003). Administration time: 15 minutes.

There were a variety of instruments developed for evaluating family functioning, but The Family Adaptability and Cohesion Evaluation Scale (FACES) is capable of discriminating between different patterns of family functioning and it is easy to administer.

In 1978 Olson and his colleagues developed a self-report scale which became one of the standard family assessment tools, and has been used in a large number of research studies and clinical assessments. FACES has become a widely used instrument for assessing children's family relations (Henggeler, 1991)

Permission to use FACES IV Package was obtained prior to administration from Life Innovations, Inc., Minneapolis.

The FACES IV Package contains eight scales in total, six scales for *FACES IV*, and two scales for the *Family Communication* and *Family Satisfaction* scales. There are 62 items, 42 items from FACES IV and 10 on Family Communication and 10 on Family Satisfaction.

FACES IV measures the dimensions of family cohesion and family flexibility using six scales. There are two balanced scales that assess *balanced family cohesion* and *balanced family flexibility*. FACES IV also contains four unbalanced scales that assess the high and low extremes of cohesion and flexibility. There are two unbalanced scales for cohesion which are *disengaged* and *enmeshment*. There are two unbalanced scales for flexibility which are *rigid* and *chaotic*.

For storing and scoring the data, an Excel file was created automatically to score the data.

In the circumplex model (Olson 2000; Olson, 1989), cohesion is defined as the degree of emotional bonding between family members. High or low levels indicate either enmeshment or disengagement. Adaptability was defined as “the ability of the family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress” (Olson et al., 1983, p. 70). High or low levels indicate either chaos or rigidity. Communication is the third dimension in Olson’s circumplex model that indicates a strong relationship between communication and levels of cohesion and adaptability.

The basic hypotheses related to the Circumplex Model were as follows:

- Balanced levels of cohesion and flexibility are more conducive to healthy family functioning.
- Unbalanced levels of cohesion and flexibility are associated with more problematic family functioning.
- Balanced systems have better communication and greater family satisfaction.

### 8.7.2 Semi-structured interview

Grix (2002) suggested that the interview is a very popular method which allows a degree of flexibility. To ensure that participants had the opportunity to discuss freely issues related to their child and family, a semi-structured interview was used (Appendix 3).

The first part of the semi-structured interview contained personal information (I.D, age, diagnosis, gender, participants and family composition: gender, age, marital status, education, impairment, employment). The interview continued with questions about the age when child was diagnosed and the length of diagnostic process. A set of questions focused on parent's feelings during the diagnostic process; changes in family life; first thoughts when received the diagnosis; main worries; experience of sibling and the extended family; and the role of mother and father in raising a child with ASD. Families were also asked about how their child's diagnosis affected the relationship between them, their siblings and the extended family. Question number 16 included the experience of aunts, uncles and cousins. Their experience was not included in the present research as actual family composition did not include them as family members.

Another set of questions concentrated on parents' involvement (information about children with ASD from Ireland and Romania; a regular day with their child and what they do for their child at home; participation in support groups; sharing the diagnosis with others; and any other questions at the end of the interview). Other questions were focused on the parents' perception about improvements in the process of diagnosis. Questions were also asked about accessibility to services.

Particular emphasizes was put on parents' feelings and their strength to talk about such a sensitive subject was consistently acknowledged. Finally, parents have had the opportunity to make remarks, observation or to discuss a particular problem.

The process of categorising parents' responses included the abstraction concept. Data derived from open-ended questions were categorised based on parents' responses.

Responses were counted as new when parents did not mention what other parents mentioned. The new responses were added to the list and incorporated in other parent's answers.

For Romanian families, the English version of Participant Information and Consent Form (Appendix 1 and 2) as well as FACES IV (Appendix 6) were translated from English into Romanian (Appendix 4, 5 and 7).

The English version of the interview (Appendix 3) was translated simultaneously while interviewing the family. As the researcher is of Romanian origin, the back translation was used to ensure validity. See Appendix 8 for Romanian version of the interview. Back translation is recommended for cross cultural studies (Brislin, 1970).



## 8.8. Procedure

### 8.8.1 Ethical considerations

Ethical approval was granted by the QUB School of Education Research Ethics committee in March 2009. In December 2009, ethical applications were submitted and approved by Cherry Orchard Hospital Dublin (Ireland) and Association Casa Faenza (Romania).

The research protocol for each study sample was approved by Queens University Belfast. The School of Education, Research Ethics Committee from Queen's University of Belfast granted ethical approval for this study. Prior to interview, parents received an information pack providing detailed information about the study and a consent form indicating that confidentiality and anonymity would be carefully maintained.

All interviews were conducted in the families homes and audio-taped. Confidentiality was specified before and after each family meeting. Participants were verbally informed that they would receive a written summary of the findings at the end of the study, if they wanted it. Participants were provided with contact details of the university, researcher and supervisors of the research. Two applications for ethical approval were prepared and submitted to Cherry Orchard Hospital Dublin (Ireland) and Association Casa Faenza (Romania) prior to commencement of data collection.

The data are kept securely for verification for five years in a locked room/encrypted computer at the School of Education. The data contains: FACES IV questionnaires, interviews, notes, audio recordings, consent forms and parents' signature and parent information forms for both Irish and Romanian families.

As the researcher's first language is not English, the thesis was reviewed by a qualified proofreader.

### 8.8.2 Recruitment

This study was based on voluntary participation; there was no financial or other compensation for participation. Participants were contacted by phone and invited to participate. Meetings were arranged in the family home. Participant information and consent forms were used (Appendix 1, 2–Irish families, 4 and 5–Romanian families).

Participants were recruited from one institution in Romania and one institution in Ireland; A total of 24 families from Cherry Orchard Hospital, Dublin and 30 families from Association “Casa Faenza” Community Centre for children with autism, Timisoara, Romania took part.

As mentioned, these two institutions constituted a convenient sample; having worked as educational psychologist at Casa Faenza Romania and senior social work practitioner in Cherry Orchard Hospital. However, my relationship with the participants in this study was strictly for research purposes only.

#### *Cherry Orchard Hospital, Early Intervention Team (EIT) –Dublin West*

EIT team is a community team that aims to achieve effective, well-coordinated interdisciplinary support for young children with developmental delays and their families. As the social worker for this team, the researcher was involved in working with many families who have children diagnosed with ASD. Approximately 80% of our clients are children with ASD.

#### *Association “Casa Faenza” Romania*

Association Casa Faenza, Community Centre for children with autism offers services for children with ASD:

The objective set based on an evaluation of the needs of the community is to improve the living conditions and the social adaptability of local children

with autistic spectrum disorders, aged 3-15, through habilitation and social integration, laying stress on early intervention.

(Primaria Timisoara, 2009).

In January 2010, meetings were arranged with contact persons from Cherry Orchard Hospital Dublin: Brigid O'Donovan (Ireland); and Association Casa Faenza: Cristina Piscuc (Romania) in order to start data collection. Data collection started in November 2011 due to maternity leave and temporary withdrawal.

### 8.8.3 Data collection

Data collection started in November 2011 and was completed in June 2013. Interviews were tape-recorded. Tape recordings were transcribed and, together with interview notes, coded individually on EXCEL and SPSS 20 (Statistical Package for the Social Science) in preparation for the statistical analysis of data. SPSS License was obtained from Queens University Belfast, Information Services Computer Shop.

*The meeting* with families included:

- 5 minutes to inform parents about the present study, family consent form and instruments used;
- 15 minutes FACES IV instructions and self-administration;
- 40 minutes to 1 hour: semi-structured interview.

The first contact with Romanian parents was conducted by Casa Faenza, by Dr. Anca Sabau, Child Psychiatrist. For Irish families the first contact with parents was established by Cornelia Munteanu, in Cherry Orchard Hospital or by phone contact, in order to inform them about the research and meet them afterwards.

Eligible family names and phone numbers were provided by contact persons from both clinics (Association Casa Faenza, Cherry Orchard Hospital). Eligible Irish and Romanian families were contacted and asked verbally to participate in this research. Meetings were arranged with those who agreed. Suitable times for meetings were arranged in order to facilitate the whole family.

At the beginning of the meeting the researcher verbally informed participants about this research study, interviews, FACES IV, about the entire procedure of data collection, confidentiality, dissertation, publication, etc.

Data collection meetings were held in each family's home. Special attention was paid in managing parents' feeling regarding ASD diagnosis of their child. The researcher was a qualified educational psychologist, social worker and family therapist, who had worked with children diagnosed with autism and their families for several years

As such she was sensitive to issues arising during the research process. Families who were experiencing particular difficulties were referred to family services provided in the centres. Alternatively, issues that arose were discussed with managers and clinicians from both institutions. Parents agreed to discuss their family issues with clinicians from both institutions.

After reading the participant information sheet (either read by participant or read out by researcher, whichever was preferred) and signing the consent form, the semi-structured interview schedule (Appendix 3) was used flexibly, i.e. during the course of interview the order of questions was slightly changed depending on the responses. For example, when parents were asked about their experience regarding accessing services for their child (question 10), and they were happy or unhappy in relation to the waiting time for diagnosis, the researcher continued with question number 19 (How do you think the diagnosis process could be improved where you live?).

When parents' response was "other parents" to question 5 (Who did you discuss your child's diagnosis with (e.g. family members, extended family, friends, professionals etc), the researcher continued with the last part of question 7 (Did you discuss with other parents who have children diagnosed with autism and if so, did you find this helpful?)

The duration of interview was approximately 40–60 minutes. Interviews were tape-recorded only when participants agreed to this. One family from Romania and one family from Ireland refused to be audio-taped. The researcher spent additional time with these families in order to be able to capture all of the verbal information provided.

Families then were asked to complete FACES IV, while the researcher temporarily left the room for approximately 15–20 minutes, or until participants informed the researcher that they had finished. Completed FACES questionnaires were placed into the envelopes provided and given to researcher on her return to the interview room. Before she left, the researcher thanked the family verbally for their participation and cooperation.

During the process of data collection, a relatively large number of Irish families refused to participate in this research, or accepted initially and later refused to participate or stated that they are very 'busy'. A total number of 77 Irish families were contacted by the researcher in order to ask for their participation in this research study. Only 24 families choose to participate in this study and 53 refused to participate. In contrast, all 30 Romanian families who were contacted to participate in this research, agreed to participate.

As a consequence of the large number of Irish families who refused to participate, the data collection was reduced to one phase. Phase 1 was conducted with 30 participants from Romania and 24 families from Ireland and included semi-structured interviews and FACES IV. Individual case studies (one from Romania and one from Ireland) had been planned to include genograms, in-vivo observations and in-depth interviews. Due to lack of participation from Irish families, the planned case studies were not conducted.

## 9. Results and data analysis

Tape recordings were transcribed and, together with interview notes, coded individually on Excel and SPSS (Statistical Package for the Social Science) in preparation for the statistical analysis of data. Electronic resources (Word files, Excel) were used for data storage. Codes were used in place of full names or addresses.

For storing and scoring FACES IV, an Excel file was created automatically to score the data.

For storing and scoring of the data from the interviews, SPSS 20 was used. SPSS is a complete system for analysing data and is probably the most common software package for statistical analysis in social science.

SPSS Statistics 20 is a comprehensive system for analysing data. SPSS Statistics can take data from almost any type of file and use them to generate tabulated reports, charts, and plots of distributions and trends, descriptive statistics, and complex statistical analyses. Data analysis usually is divided into two types: exploratory and confirmatory (Robson, 2002). In this research, the exploratory type described and explored the data.

The first step in data analysis was to calculate descriptive statistics and to establish distributions. Descriptive statistics describe the main aspects of a data collection. The most common ones are the level of the distribution and its spread (dispersion). Statistics summarizing the level of distribution are called measures of central tendency. Statistics summarizing the spread are called measures of variability. The distribution is also called 'Gaussian' distribution. The shape of the distribution is determined by the mean and standard deviation.

The most common statistics used for measures of central tendency are: mean, median and mode. The most common statistics used for measures of variability are range, inter-quartile range, variance, standard deviation and standard error. Cross tabulation

would show whether or not there is a relationship between two variables. Chi-square or 'Pearson chi-square' is a measure of the degree of association between two variables. The t-test is commonly used to compare the means of one group, two groups or more than two groups. In this research the t-test used is the unpaired two-group t-test. This is applicable where there is no such basis for putting together pairs of scores.

The purpose of a study is to answer the question 'Have we got a significant result?' 'Is  $p < 0.05$ ?' (Robson, 2002). 'p' refers to statistical significance .



### 9.1. Semi-structured interview results

The first part of the semi-structured interview included information about children's age, gender, participants, family composition (gender, age, marital status, education, level of impairment and employment)

#### *Children's age and gender*

The majority of children who participated in this study were boys in both countries. In Ireland, twenty-four children in total: 20 boys and 4 girls. In Romania, 30 children, 27 boys and 3 girls. Table 9-1 shows the distribution of child's gender in both groups.

Table 9-1. Distribution of child's gender for Irish and Romanian groups

	Ireland	Romania
male	20	27
female	4	3
Total	24	30

In terms of children's age and frequency of age in both countries, the Irish group shows that majority of children were between 4 and 5 years olds. In the Romanian group, the children's ages vary at between 3 and 5 years. Table 9-2 shows children's age and frequency of age.

Table 9-2. Children's age and frequency of age (Irish vs Romanian).

Child age (years)	Ireland	Romania
2	0	1
3	3	6
4	8	13
5	11	7
6	1	3
7	1	0

The descriptive statistics in Table 9-3 show that the average of child's age in Ireland was 52.92 months, while in Romania, the average age of children was 46.77 months.

The results of average age show that children from the Romanian group were approximately 6 months younger than the Irish children.

Table 9-3. Descriptive statistics for child's age (Irish vs Romanian).

	Country	Mean	Std. Deviation
Child age (months)	Ireland	52.92	10.713
	Romania	46.77	13.045

### *Parents' gender and age*

Participants who agreed to take part in this study were 24 families from Ireland (majority were mothers – 20) and 30 families from Romania (majority were mothers – 24) as presented in Table 9-4.

Table 9-4. Number of participants (Irish vs Romanian).

Participant	Ireland	Romania
father	1	2
mother	20	24
mother, father	3	4
Grand total	24	30

Table 9-5 shows the age and numbers of mother and fathers in both countries who participated in this study.

Table 9-5. Age of mother and father (Ireland and Romania).

	Age of mother		Age of father	
	Ireland	Romania	Ireland	Romania
21-25	0	2	2	1
26-30	9	2	3	1
31-35	3	15	5	8
36-40	4	6	2	9
41-45	5	5	5	6
46-50	2	0	2	2
51-55	0	0	2	0
56-60	0	0	0	1

In Ireland, the age of mothers is between 26 and 50 years. Fathers' age is between 21 and 55 years. In Romania, the age of mothers is between 21 and 45 years. Fathers' age is between 21 and 60 years. The most frequent age of mothers in Ireland was between 26–30 years. In Romania, the most frequent age range of mothers was between 31–35 years, as shown in Figure 9-1.

Figure 9-2 shows the distribution of father's age in both countries. The most frequent age interval of fathers in Romania was between 31–40 years and the most frequent age interval of fathers in Ireland was between 31–35 years and 41–45 years.

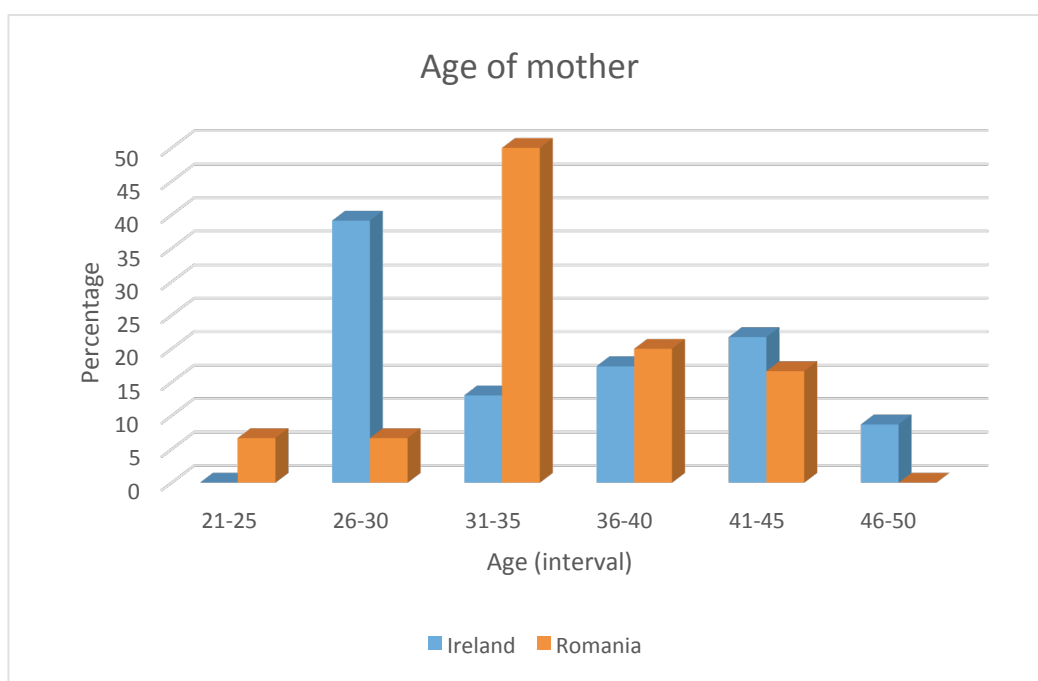


Figure 9-1. Distribution of mother's age (Irish vs Romanian).

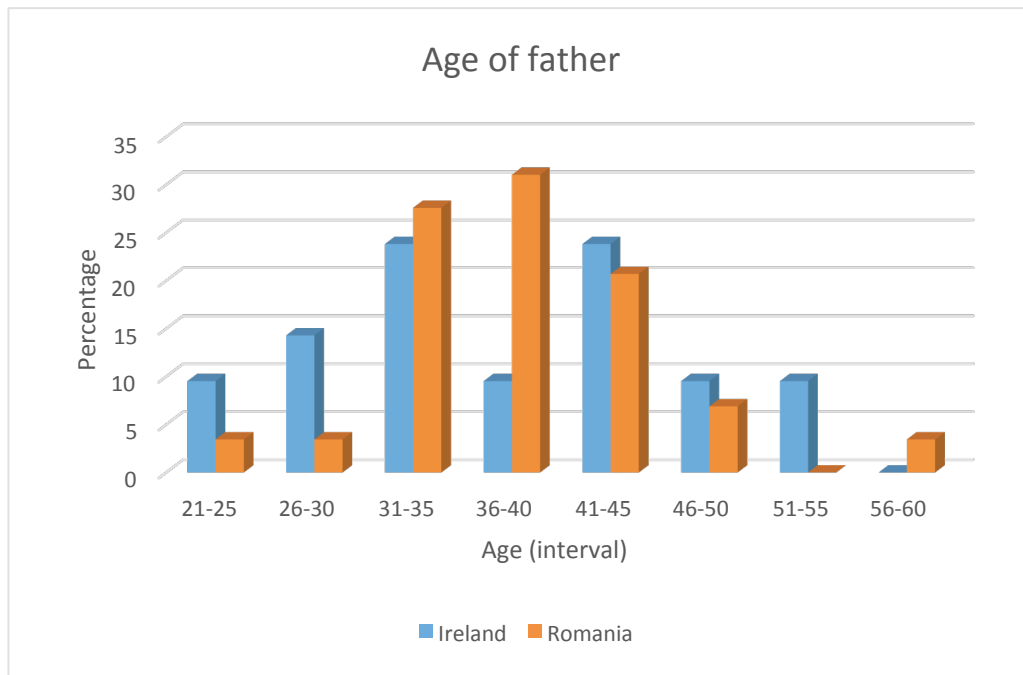


Figure 9-2. Distribution of father's age (Irish vs Romanian).

The descriptive statistics in Table 9-6 show that the average age of mothers in Ireland was 35.57 and the average age of father was 37.43. The average age of mothers in Romania was 34.67 and the average age of father was 37.71.

Table 9-6. Descriptive statistics of mother's and father's age

	Country	N	Mean	Std. Deviation
Mother's age	Ireland	23	35.57	7.519
	Romania	30	34.67	5.248
Father's age	Ireland	21	37.43	9.053
	Romania	28	37.71	6.399

### *Parents' level of education*

Table 9-7 shows parents' level of education and both countries. In Ireland, the level of education of mothers and fathers with children with ASD was predominantly secondary level. In Romania, the level of education of mothers and fathers with children with ASD was primarily third level.

Table 9-7. Mother's and father's education (Irish vs Romanian).

	Mother's education		Father's education	
	Ireland	Romania	Ireland	Romania
primary	1	0	1	0
secondary	14	8	14	11
third level	8	22	6	18

Figure 9-3 shows mother's education distribution in Ireland and Romania. In Ireland, mother's education was predominantly secondary (between 50-60%) and in Romania, the mother's education was generally third level (70%)

Figure 9-4 shows father's education distribution in Ireland and Romania. In Ireland, father's level of education was predominantly secondary (between 60–70%) and in Romania, father's level of education was generally third level (50–60%).

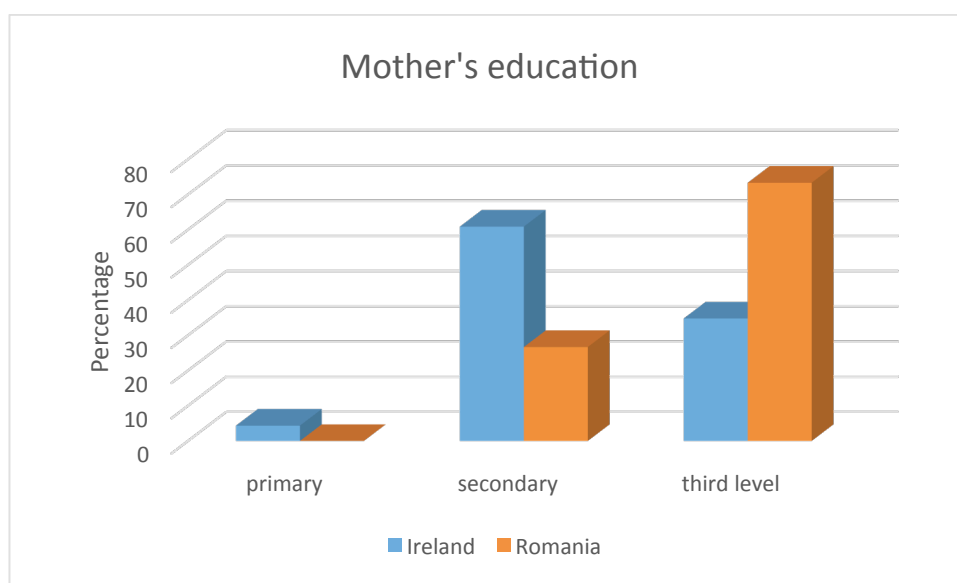


Figure 9-3. Distribution of mother's education (Irish vs Romanian).

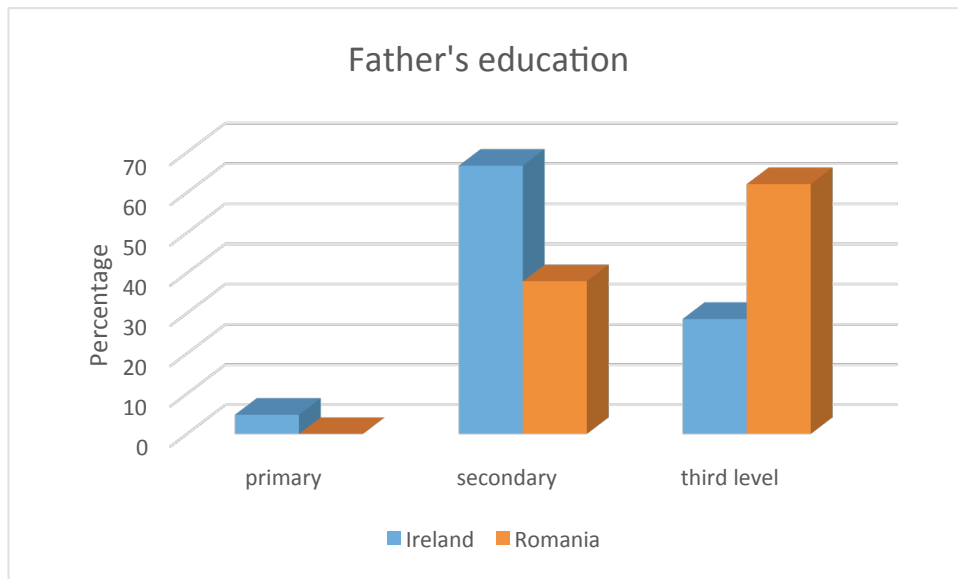


Figure 9-4. Distributions of father education (Irish vs Romanian).

### *Employment status*

Table 9-8 shows the employment status of mothers and fathers in both countries. In Ireland, 16 of the mothers were not working and 8 of the fathers were not working, while 7 mothers were working and 13 fathers were working. In Romania, 16 of the mothers were not working and 3 of the fathers were not working, while 14 of the mothers were working and 26 of the fathers were working.

Table 9-8. Mother's and father's employment status (Irish vs Romanian).

	Mother's employment		Father's employment	
	Ireland	Romania	Ireland	Romania
unemployed	16	16	8	3
employed	7	14	13	26

Figure 9-5 and Figure 9-6 show the distribution of mother's and father's employment status in Ireland and Romania. In Ireland, approximately 65% of mothers were not working. In Romania, approximately 49% of mothers were not working.

In Ireland, between 50–60% of fathers were working. In Romania, between 80–90% of fathers were working.

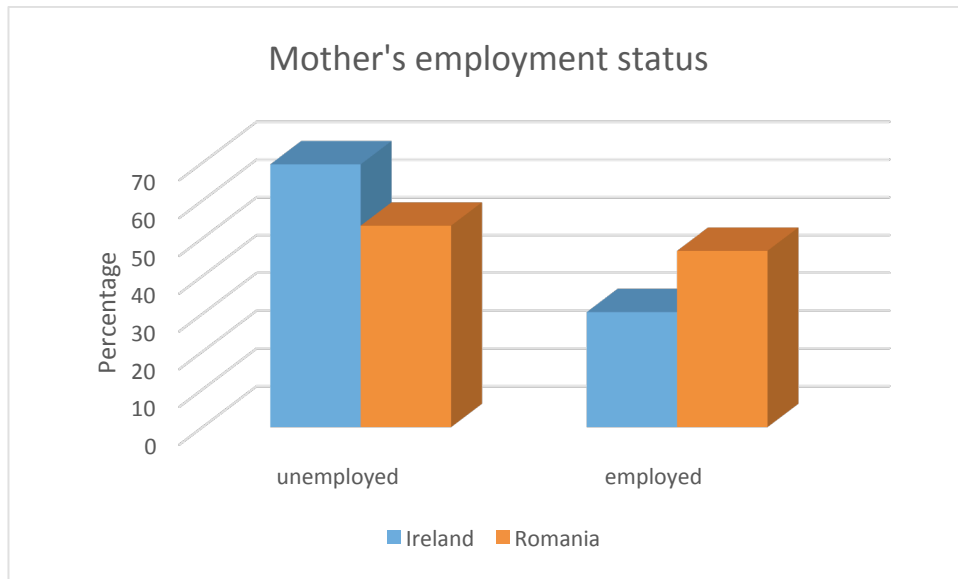


Figure 9-5. Mother's employment status distribution (Irish vs Romanian).

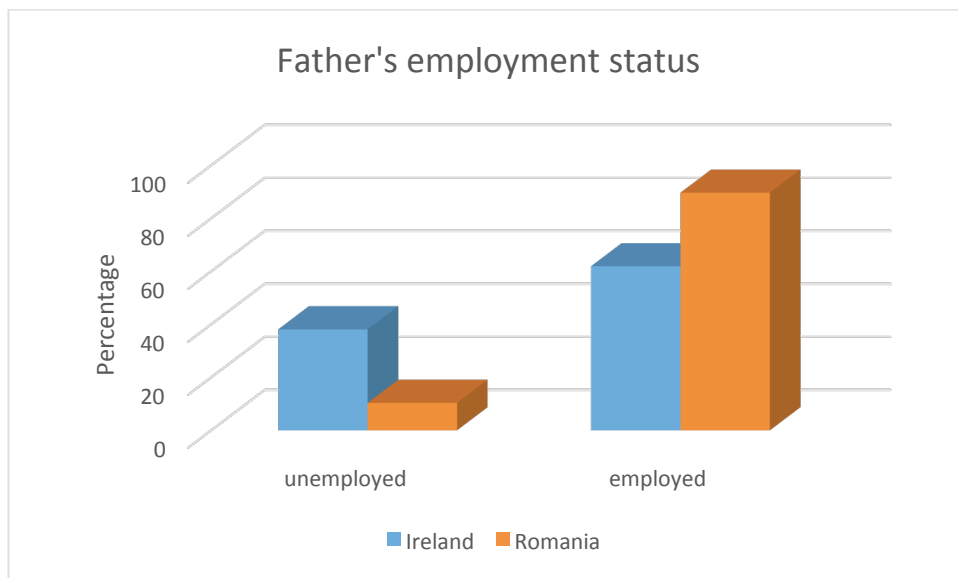


Figure 9-6. Father's employment status distribution (Irish vs Romanian).

### *Marital status*

In terms of marital status, Table 9-9 shows that in Ireland most of the families were married or single (21). In Romania, the majority (28 families) were married.

Table 9-9. Marital status (Irish vs Romanian).

Marital status	Ireland	Romania
single	7	1
cohabitating	3	1
married	14	28

Figure 9-7 shows the distribution of marital status in both countries. In Romania, between 80–90% of parents were married. In Ireland, 50–60% were married.

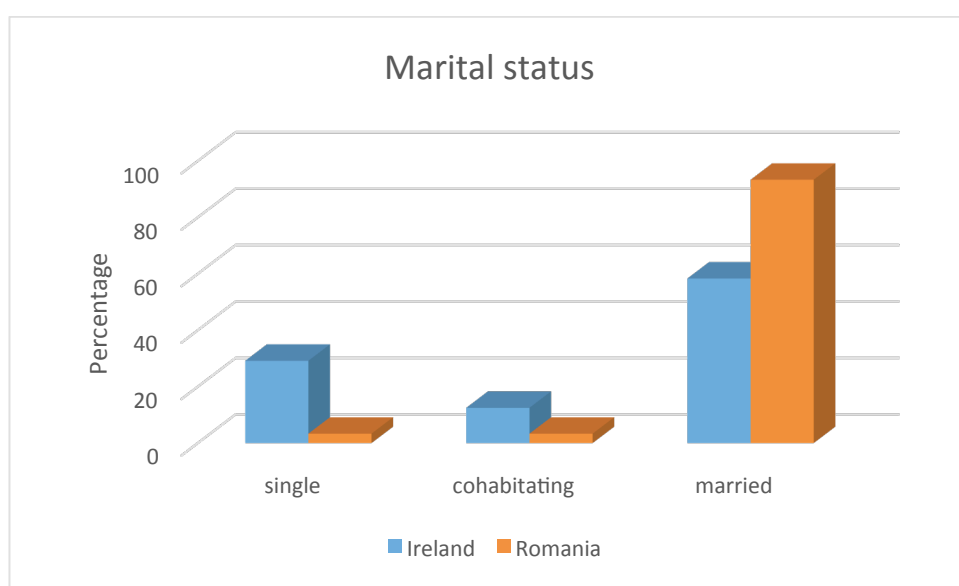


Figure 9-7. Marital status distribution (Irish vs Romanian).

### *Siblings*

Table 9-10 indicates the number of siblings in Irish families ranged from 0 to 7. In Romania, most children with ASD had no siblings (n=21) or one sibling. In Ireland, most of children with ASD had at least one sibling (n=10) or more (n=8).

Table 9-10. Number of siblings (Irish vs Romanian).

Siblings	Ireland	Romania
0	6	21
1	10	8
2	4	1
3	2	0



4	0	0
5	0	0
6	0	0
7	2	0

The distribution of number of siblings in Ireland and Romania in Figure 9-8 shows that approximately 70% of Romanian children with ASD had no siblings. In Ireland, 20–30% of children with ASD had no siblings, 40% had 1 sibling and 15% had 2 siblings.

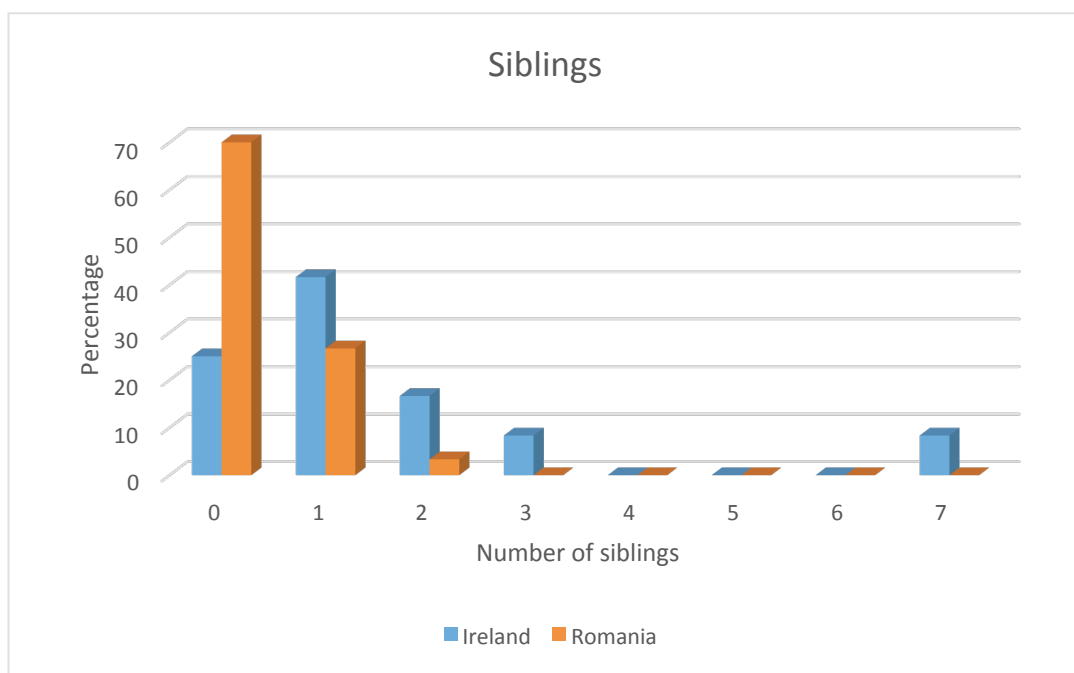


Figure 9-8. Number of siblings distribution (Irish vs Romanian).

The next two questions of the semi-structured interview included the age of the child when diagnosed and the duration of the diagnostic process.

#### *Age when diagnosed*

Table 9-11 shows the age of children when they received the ASD diagnosis in both countries.

Table 9-11. Age when diagnosed (Irish vs Romanian).

Age (years)	Ireland	Romania
2	0	5
3	10	14
4	10	10
5	3	1
6	1	0

Figure 9-9 below shows the distribution of age when diagnosed in years.

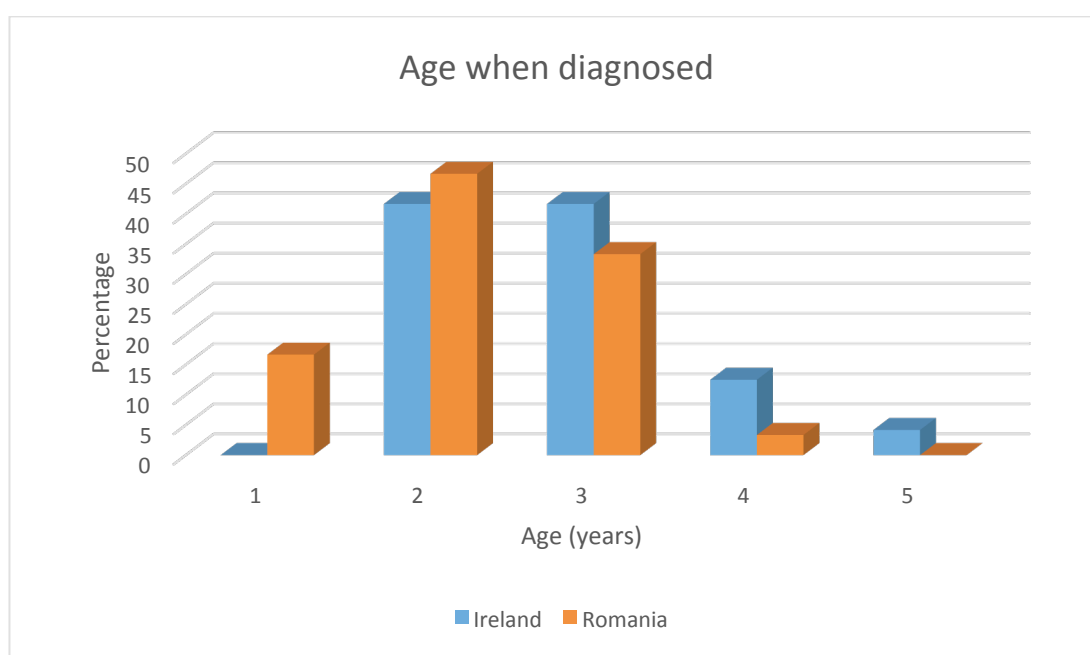


Figure 9-9. Distribution of age when diagnosed (Irish vs Romanian).

Descriptive statistics in Table 9-12 show that the average age (in months) when the diagnosis of ASD was received in Ireland was 42.75 months and the average age when the ASD diagnosis was received in Romania was 36.03 months. The results show that children in Romania were diagnosed somewhat earlier.

Table 9-12. Descriptive statistics of age when diagnosed.

	Country	Mean	Std. Deviation
Age when diagnosed (months)	Ireland	42.75	9.018
	Romania	36.03	10.420

### *Duration of diagnostic process*

Figure 9-10 shows the length of time it took for the diagnosis in Ireland and Romania using intervals from <6 months to 25-30 months. In Romania, 70–80% of children were diagnosed before 6 months, 40–50% were diagnosed between 7–12 months, 10–20% were diagnosed between 13–18 months, and 20–30% were diagnosed between 19–24 months. In Ireland, 0–10% were diagnosed before 6 months, 40–50% were diagnosed between 7–12 months, 10–20% were diagnosed between 13–18 months, 20–30% were diagnosed between 19–24 months, 0–10% were diagnosed at between 25–30 months.

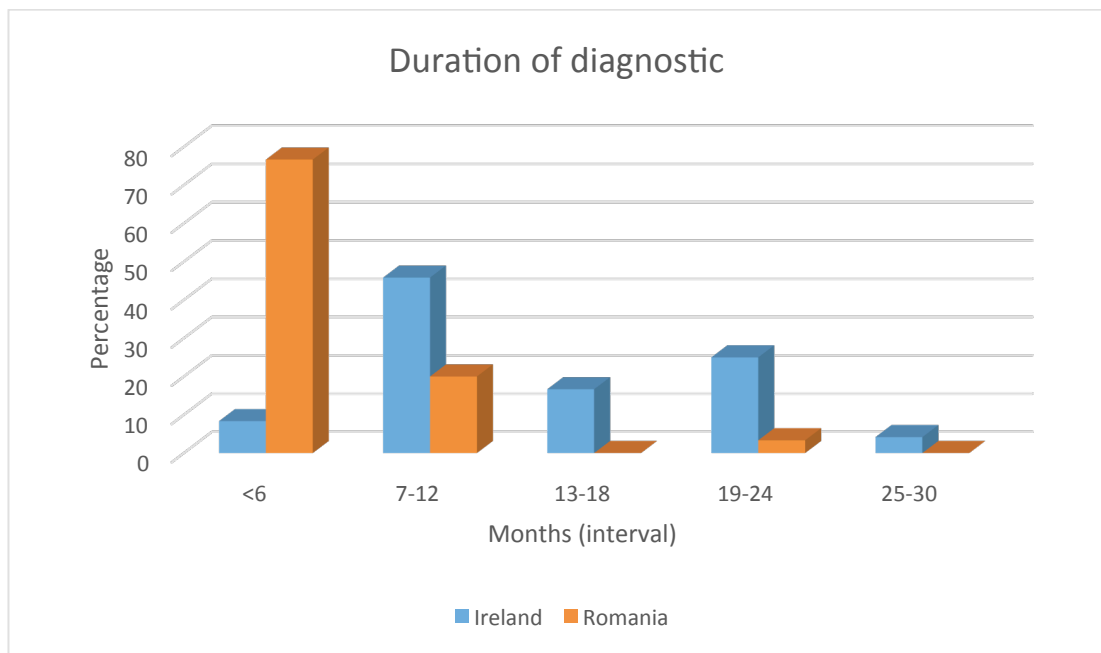


Figure 9-10. Distribution of duration of diagnostic process (Irish vs Romanian).

The length of time taken for the diagnostic process in Ireland and Romania was calculated in months (Table 9-13). The average duration of diagnostic process in the Romanian group was 4.63 months and the average duration of diagnostic process in the Irish group was 14.92 months. In the Romanian group, the process of diagnosis was 10 months faster than the Irish group.

Table 9-13. Descriptive statistics of duration of the diagnostic process.

	Country	Mean	Std. Deviation	Mean Difference	% Mean Difference	Significant?
Duration of diagnosis (months)	Ireland	14.92	6.940	10.283	69%	Yes
	Romania	4.63	5.255			

According to the t-test (Table 9-14), the difference between the means of two groups was statistically significant ( $p < 0.05$ ) in terms of duration of diagnostic process.

Table 9-14. Duration of diagnosis: t-test results for equality of means.

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Duration of diagnosis (months)	6.010	41.942	.000	10.283	1.711

Table 9-15 shows below that the average post-diagnostic stage was an average of 10 months for both groups.

Table 9-15. How long ago was the child diagnosed: descriptive statistics.

	Country	Mean	Std. Deviation	Difference
How long ago child was diagnosed (months)	IE	10.17	6.989	-0.56
	RO	10.73	6.591	

## 9.2. FACES IV results

The background information from FACES IV include similar information as was described in the semi-structured interview: age, sex, education, marital status, number of children in family, family structure. New information was related to income and ethnic background.

All participants (n=54) in this study were white/Caucasian. The distribution of income in both countries, Ireland and Romania, is represented below in Figure 9-11. In Romania, the majority of parents declared that their income was less than €10,000. In Ireland, the income varied.

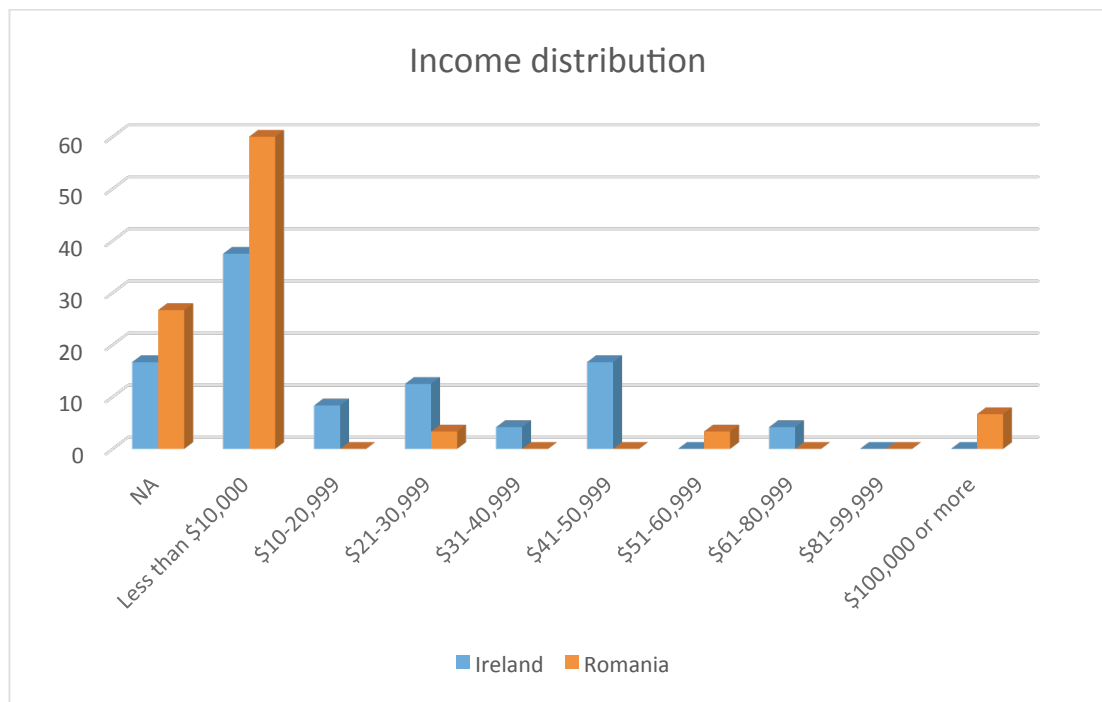


Figure 9-11. Income distribution (Irish vs Romanian).

### 9.2.1. Balanced and unbalanced scores

As mentioned, the first 42 items from FACES IV measure the dimensions of family cohesion and family flexibility using six scales. The rest of the 20 items measure

family communication (10 items) and family satisfaction (10 items). There are two balanced scales that assess *balanced family cohesion* and *balanced family flexibility*.

FACES IV also contains four unbalanced scales that assess the high and low extremes of cohesion and flexibility. There are two unbalanced scales for cohesion which are *disengaged* and *enmeshment*. There are two unbalanced scales for flexibility which are *rigid* and *chaotic*.

FACES IV created an Excel file for subjects' answers that automatically scored the data. The Excel program took each item response and summed them for each of the six FACES IV scales: *balanced cohesion*, *balanced flexibility*, *disengaged*, *enmeshed*, *rigid* and *chaotic*. The total raw score was converted into percentage score using the percentile conversion chart.

Table 9-16 shows balanced and unbalanced percentile scores for each participant (n=24) in the Irish group. Balanced cohesion percentile scores contain three levels: *somewhat connected (16–35)*, *connected (36–65)* and *very connected (68–85)*. Balanced flexibility percentile scores contain three levels: *somewhat flexible (16–35)*, *flexible (between 36–65)* and *very flexible (68–85)*. The four unbalanced percentile scores (disengaged, enmeshed, rigid and chaotic) contain five levels: *very low (10–26)*, *low (30–40)*, *moderate (45–60)*, *high (64–75)* and *very high (80–99)*.

Table 9-16. Balanced and unbalanced scores: list of families in Ireland.

Subj ect ID	Balanced Cohesion % Score	Balanced Flexibility % Score	Disengaged % Score	Enmeshed % Score	Rigid % Score	Chaotic % Score
1	82	62	18	55	70	15
2	82	62	16	14	40	34
3	82	68	12	10	13	10
4	84	80	10	12	16	24
5	70	60	15	14	36	24
6	80	75	16	13	32	18
7	75	80	26	18	24	40
8	80	68	13	60	50	18
9	50	40	45	70	75	85
10	82	60	18	26	45	14
11	65	55	16	18	55	15
12	85	80	15	20	24	24
13	84	70	36	14	26	26
14	68	45	15	10	40	20

15	85	80	24	75	55	18
16	68	50	18	20	45	18
17	82	62	14	18	30	13
18	85	70	13	15	26	10
19	68	45	18	16	32	24
20	82	62	20	20	50	12
21	68	50	36	26	34	16
22	84	62	10	12	55	14
23	70	55	18	24	36	32
24	65	60	55	45	60	36

Table 9-17 shows the average of balanced and unbalanced scores in the Irish group as follows: 76.08 average score for balanced cohesion, 62.54 average score for balanced flexibility, 20.71 average score for disengaged, 26.04 average score for enmeshed, 40.38 average score for rigid and 23.33 average score for chaotic.

Table 9-17. Balanced and unbalanced scores: descriptive statistics (Ireland).

	Minimum	Maximum	Mean	Std. Deviation
Balanced Cohesion % Score	50	85	76.08	9.160
Balanced Flexibility % Score	40	80	62.54	11.643
Disengaged % Score	10	55	20.71	11.312
Enmeshed % Score	10	75	26.04	19.477
Rigid % Score	13	75	40.38	16.086
Chaotic % Score	10	85	23.33	15.494

The distribution of balanced and unbalanced levels in the Irish group is represented in Figure 9-12. Balanced cohesion shows 80–90 percentile very connected levels. Balanced flexibility shows flexible (>60) and very flexible levels (30–40). Disengaged, enmeshed and chaotic show very low levels. The rigid level is low and moderate.

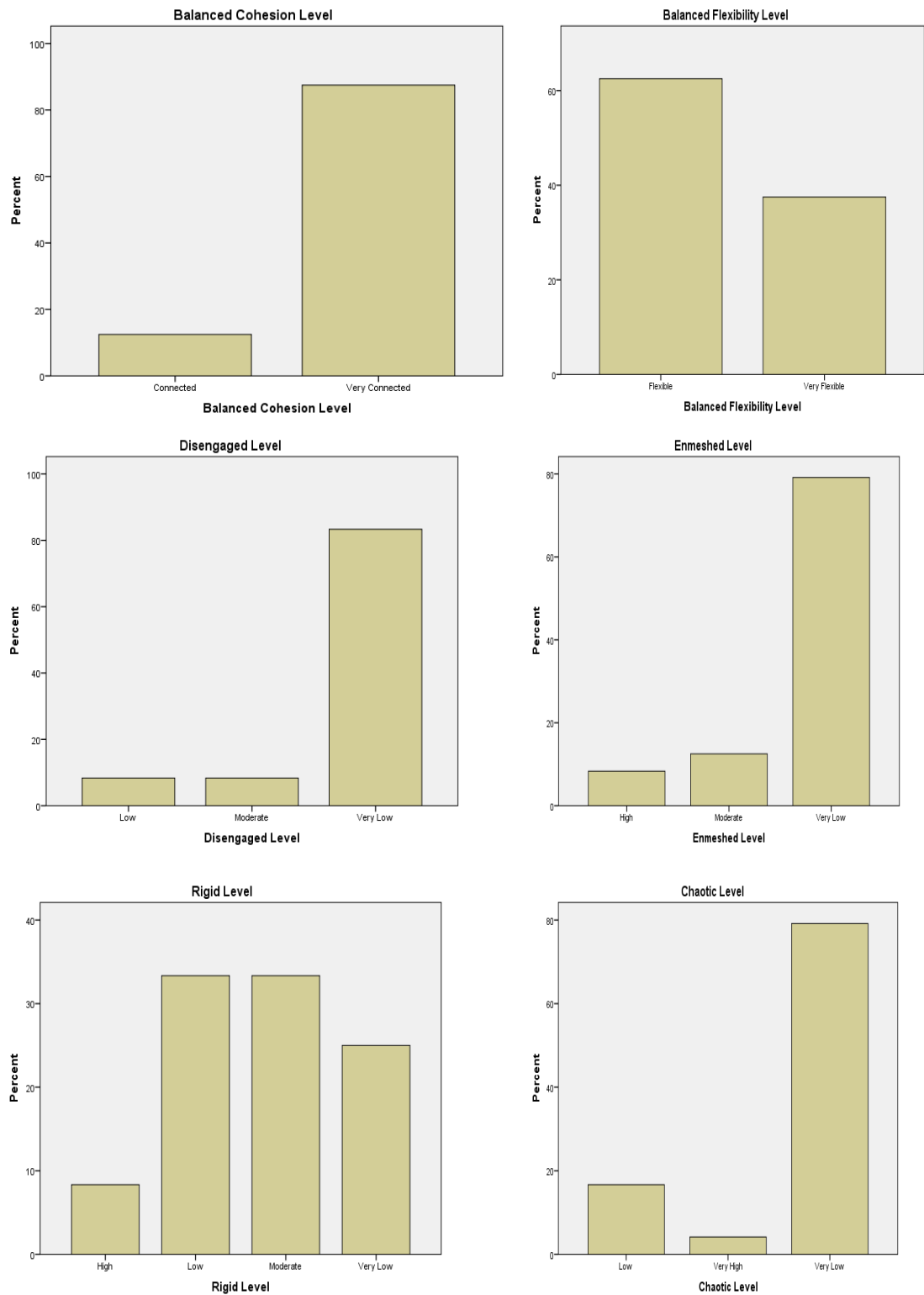


Figure 9-12. Balanced and unbalanced levels: distributions (Ireland).

Table 9-18 shows balanced and unbalanced percentile scores for each participant (n=30) in the Romanian group. Balanced cohesion percentile scores contain three



levels: *somewhat connected (16–35)*, *connected (36–65)* and *very connected (68–85)*. Balanced flexibility percentile scores contain three levels: *somewhat flexible (16–35)*, *flexible (36–65)* and *very flexible (68–85)*. The four unbalanced percentile scores (disengaged, enmeshed, rigid and chaotic) contain five levels: *very low (10–26)*, *low (30–40)*, *moderate (45–60)*, *high (64–75)* and *very high (80–99)*.

Table 9-18. Balanced and unbalanced scores: list of families in Romania.

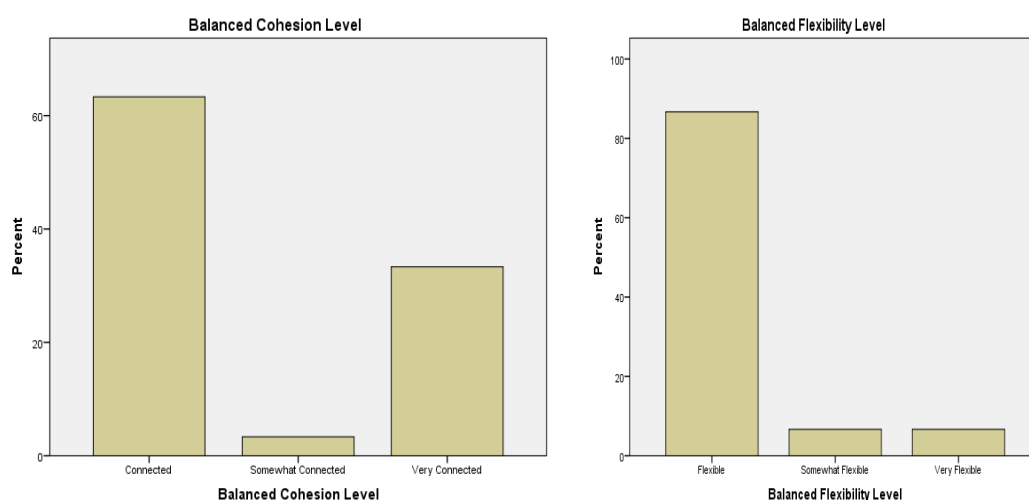
Subject ID	Balanced Cohesion % Score	Balanced Flexibility % Score	Disengaged % Score	Enmeshed % Score	Rigid % Score	Chaotic % Score
1	68	62	18	36	55	13
2	60	40	12	12	14	16
3	82	68	34	60	64	64
4	84	58	15	15	30	30
5	62	55	26	36	36	36
6	58	50	36	36	60	24
7	30	27	45	24	13	50
8	62	50	45	45	26	50
9	65	55	12	26	24	13
10	68	58	20	20	30	34
11	62	45	20	32	34	26
12	84	58	16	16	36	16
13	65	55	24	50	55	20
14	82	60	26	30	32	26
15	62	60	34	45	34	55
16	60	60	20	18	34	36
17	45	55	50	34	26	50
18	65	58	30	34	34	26
19	80	62	15	40	30	18
20	65	75	16	26	32	26
21	58	50	50	32	40	36
22	65	65	15	32	60	15
23	75	58	16	16	32	26
24	80	65	15	32	34	24
25	65	45	34	40	32	34
26	75	62	16	20	40	16
27	65	32	32	32	32	15
28	40	36	50	50	64	34
29	60	65	26	36	26	26
30	60	55	34	40	45	45

Table 9-19 shows the average of balanced and unbalanced scores in the Romanian group as follows: 65.07 average score for balanced cohesion, 54.80 average score for balanced flexibility, 26.73 average score for disengaged, 32.17 average score for enmeshed, 36.80 average score for rigid and 30.00 average score for chaotic.

Table 9-19. Balanced and unbalanced scores: descriptive statistics (Romania).

	Minimum	Maximum	Mean	Std. Deviation
Balanced Cohesion % Score	30	84	65.07	12.390
Balanced Flexibility % Score	27	75	54.80	10.682
Disengaged % Score	12	50	26.73	12.168
Enmeshed % Score	12	60	32.17	11.534
Rigid % Score	13	64	36.80	13.392
Chaotic % Score	13	64	30.00	13.633

The distribution of balanced and unbalanced levels in the Romanian group is represented in Figure 9-13. Balanced cohesion shows >60 percentile connected levels. Balanced flexibility shows a flexible level (>60). Disengaged level was very low and enmeshed level was low. The rigid level was low and the chaotic level was very low.



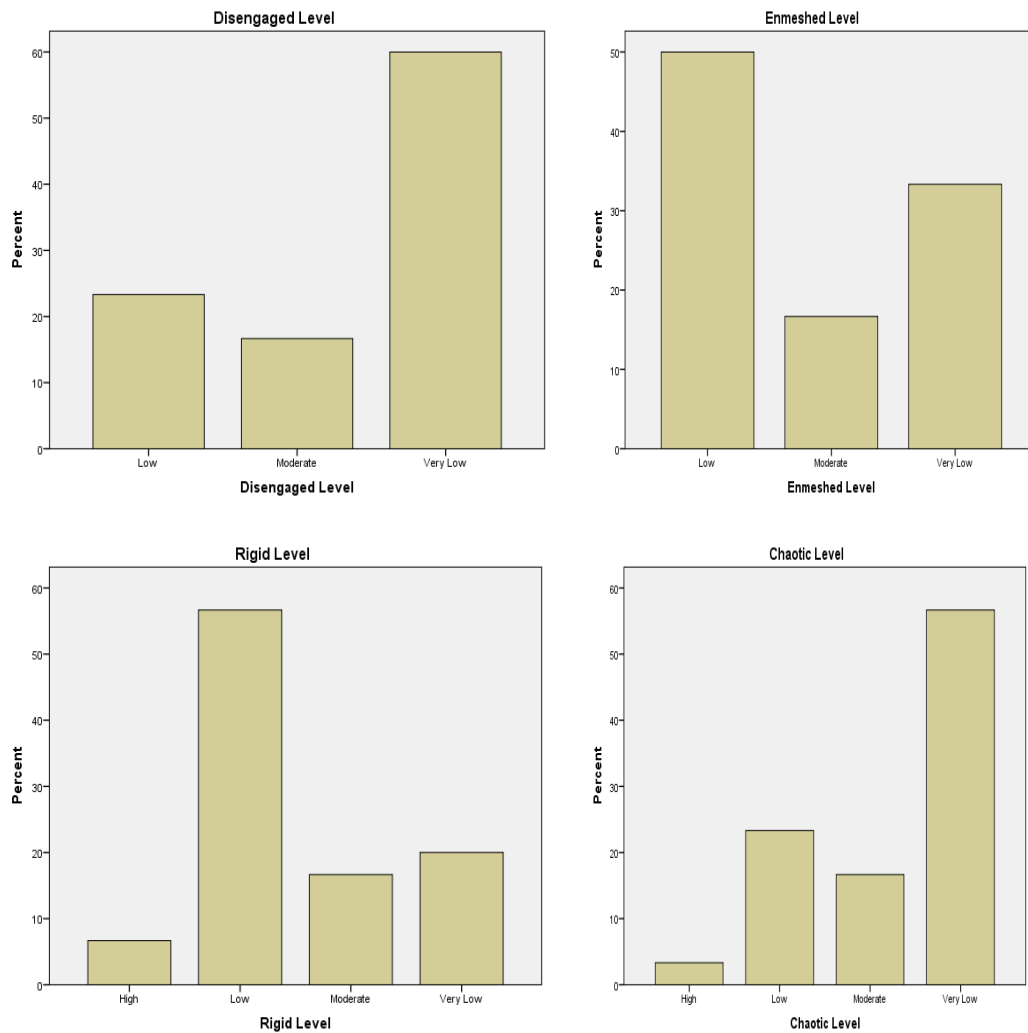


Figure 9-13. Balanced and unbalanced levels: distributions (Romania).

The Excel program created a *cohesion ratio*, *flexibility ratio*, *total circumplex ratio* scores, *cohesion dimension* and *flexibility dimension*. The Excel program summed the 10 items in the *family communication* and *family satisfaction* scales and provided a total raw score and percentile score for these two scales. All these are described subsequently.

### 9.2.2. The ratio scores

The Excel program used for FACES IV created a *cohesion ratio*, *flexibility ratio* and *total circumplex ratio* scores which will be described in detail. This balanced/unbalanced ratio score is useful as it shows the level of functional versus

dysfunctional behaviour perceived in the family system. The ratio score was obtained by assessing the balanced/average unbalanced score for each dimension.

The lower the ratio score *below one*, the more unbalanced the system. Conversely, the higher the ratio score *above one*, the more balanced the system. Table 9-20 shows the cohesion ratio, flexibility ratio and total score for each participant in the Irish group. Table 9-21 indicates that the average cohesion ratio in the Irish group was 4.16, the average flexibility ratio is 2.29 and total ratio is 3.22.

Table 9-20. Ratio scores: list of families in Ireland.

Subject ID	Cohesion ratio	Flexibility ratio	Total ratio
1	2.25	1.46	1.85
2	5.47	1.68	3.57
3	7.45	5.91	6.68
4	7.64	4.00	5.82
5	4.83	2.00	3.41
6	5.52	3.00	4.26
7	3.41	2.50	2.95
8	2.19	2.00	2.10
9	0.87	0.50	0.68
10	3.73	2.03	2.88
11	3.82	1.57	2.70
12	4.86	3.33	4.10
13	3.36	2.69	3.03
14	5.44	1.50	3.47
15	1.72	2.19	1.95
16	3.58	1.59	2.58
17	5.13	2.88	4.00
18	6.07	3.89	4.98
19	4.00	1.61	2.80
20	4.10	2.00	3.05
21	2.19	2.00	2.10
22	7.64	1.80	4.72
23	3.33	1.62	2.48
24	1.30	1.25	1.28

Table 9-21. Ratio scores: descriptive statistics (Ireland)

	Minimum	Maximum	Mean	Std. Deviation
Cohesion ratio	.86	7.63	4.16	1.91
Flexibility ratio	.5	5.91	2.29	1.12
Total ratio	.68	6.68	3.22	1.39

Table 9-22 shows the cohesion ration, flexibility ratio and total score for each participant in the Romanian group. Table 9-23 indicates that the average cohesion ratio in the Romanian group was 2.6, the average flexibility ration is 1.75 and total ratio was 2.18. The lower the ratio score *below one*, the more unbalanced the system. Conversely, the higher the ratio score *above one*, the more balanced the system.

Table 9-22. Ratio scores: list of families in Romania.

<i>Subject ID</i>	Cohesion ratio	Flexibility ratio	Total ratio
1	2.52	1.82	2.17
2	5.00	2.67	3.83
3	1.74	1.06	1.40
4	5.60	1.93	3.77
5	2.00	1.53	1.76
6	1.61	1.19	1.40
7	0.87	0.86	0.86
8	1.38	1.32	1.35
9	3.42	2.97	3.20
10	3.40	1.81	2.61
11	2.38	1.50	1.94
12	5.25	2.23	3.74
13	1.76	1.47	1.61
14	2.93	2.07	2.50
15	1.57	1.35	1.46
16	3.16	1.71	2.44
17	1.07	1.45	1.26
18	2.03	1.93	1.98
19	2.91	2.58	2.75
20	3.10	2.59	2.84
21	1.41	1.32	1.37
22	2.77	1.73	2.25
23	4.69	2.00	3.34
24	3.40	2.24	2.82
25	1.76	1.36	1.56
26	4.17	2.21	3.19
27	2.03	1.36	1.70
28	0.80	0.73	0.77
29	1.94	2.50	2.22
30	1.62	1.22	1.42

Table 9-23. Ratio scores: descriptive statistics (Romania).

	Minimum	Maximum	Mean	Std. Deviation
Cohesion ratio	.8	5.6	2.6	1.3
Flexibility ratio	.73	2.97	1.75	.56
Total ratio	.76	3.83	2.18	.87

### 9.2.3. Family satisfaction and communication scores

The interpretation of scores for *family communication* is as follows:

Percentage and levels:

- Very High (86–99%) scores indicate that family members feel very positive about the quality and quantity of their family communication.
- High (61–85%) scores indicate that family members feel good about their family communication and have few concerns.
- Moderate (36–60%) scores indicate that family members feel generally good about their family communication, but have some concerns.
- Low (21–35%) scores indicate that family members have several concerns about the quality of their family communication.
- Very Low (10–20%) scores indicate that family members have many concerns about the quality of their family's communication.

Based on the above interpretation of family communication scores, Table 9-24 shows the results for each family in the Irish group. Table 9-25 indicates that the average family communication score in the Irish group was 75.88 which shows a high level of communication.

The interpretation of scores for *family satisfaction* is as follows:

Percentage and Levels:

- Very high (86–99%) scores indicate that family members are very satisfied and really enjoy most aspects of their family.
- High (61–85%) scores indicate that family members are satisfied with most aspects of their family.
- Moderate (36–60%) scores indicate that family members are somewhat satisfied and enjoy some aspects of their family.

- Low (21–35%) scores indicate that family members are somewhat dissatisfied and have some concerns about their family.
- Very Low (10–20%) scores indicate that family members are very dissatisfied and are concerned about their family.

Based on the above interpretation of family satisfaction scores, Table 9-24 shows the results for each family in the Irish group. Table 9-25 indicates that the average family satisfaction score in the Irish group was 54.58 which shows a moderate level of satisfaction.

Table 9-24. Family scores: list of families in Ireland.

<i>Subject ID</i>	Family communication % score	Family satisfaction % score
1	44	35
2	24	13
3	97	87
4	90	98
5	83	71
6	90	87
7	65	10
8	94	30
9	18	10
10	94	75
11	94	71
12	96	99
13	88	40
14	86	79
15	90	58
16	94	51
17	61	28
18	94	92
19	61	30
20	86	75
21	70	30
22	83	71
23	58	25
24	61	45

Table 9-25 .Family scores: descriptive statistics (Ireland).

	Minimum	Maximum	Mean	Std. Deviation
Family Communication % score	18	97	75.88	22.591
Family Satisfaction % score	10	99	54.58	29.050

As mentioned for the Irish group, the interpretation of scores for *family communication* was as follows:

Percentage and levels:

- Very high (86–99%) scores indicate that family members feel very positive about the quality and quantity of their family communication.
- High (61–85%) scores indicate that family members feel good about their family communication and have few concerns.
- Moderate (36–60%) scores indicate that family members feel generally good about their family communication, but have some concerns.
- Low (21–35%) scores indicate that family members have several concerns about the quality of their family communication.
- Very low (10–20%) scores indicate that family members have many concerns about the quality of their family communication.

Based on the above interpretation of family communication scores, Table 9-26 shows the results for each family in the Romanian group. Table 9-27 indicates that the average family communication score in the Romanian group was 66.17 which shows a high level of communication.

The interpretation of scores for *family satisfaction* was as follows:

Percentage and Levels:

- Very high (86–99%) scores indicate that family members are very satisfied and really enjoy most aspects of their family.
- High (61–85%) scores indicate that family members are satisfied with most aspects of their family.
- Moderate (36–60%) scores indicate that family members are somewhat satisfied and enjoy some aspects of their family.
- Low (21–35%) scores indicate that family members are somewhat dissatisfied and have some concerns about their family.
- Very low (10–20%) scores indicate that family members are very dissatisfied and are concerned about their family.



Based on the above interpretation of family satisfaction scores, Table 9-26 shows the results for each family in the Romanian group. Table 9-27 indicates that the average family satisfaction score in the Romanian group was 35.43 which shows a low level of satisfaction.

Table 9-26. Family scores: list of families in Romania.

<i>Subject ID</i>	Family communication % score	Family satisfaction % score
1	88	23
2	86	30
3	94	58
4	90	84
5	50	23
6	32	10
7	10	10
8	58	30
9	86	87
10	58	18
11	58	30
12	90	84
13	70	25
14	97	84
15	40	10
16	70	25
17	36	10
18	70	21
19	90	25
20	70	40
21	44	18
22	70	10
23	58	40
24	88	51
25	61	45
26	94	98
27	86	30
28	18	10
29	65	21
30	58	13

Table 9-27. Family scores: descriptive statistics (Romania)

	Minimum	Maximum	Mean	Std. Deviation
Family Communication % score	10	97	66.17	23.314
Family Satisfaction % score	10	98	35.43	26.715

#### 9.2.4. Average Profile

The FACES IV profile for both, the Irish group and the Romanian group is represented in Figure 9-14.

- For balanced cohesion and balanced flexibility, higher scores indicate healthier family profile.
- The unbalanced scores (disengaged, enmeshed, rigid and chaotic) show non problematic profiles (higher scores are problematic).
- For family communication and family satisfaction, higher scores represent healthier profiles.

The scores for balanced cohesion, balanced flexibility and unbalanced scores did not show significant differences between the two groups. Only, the family satisfaction score was lower in the Romanian group when compared with the Irish group.

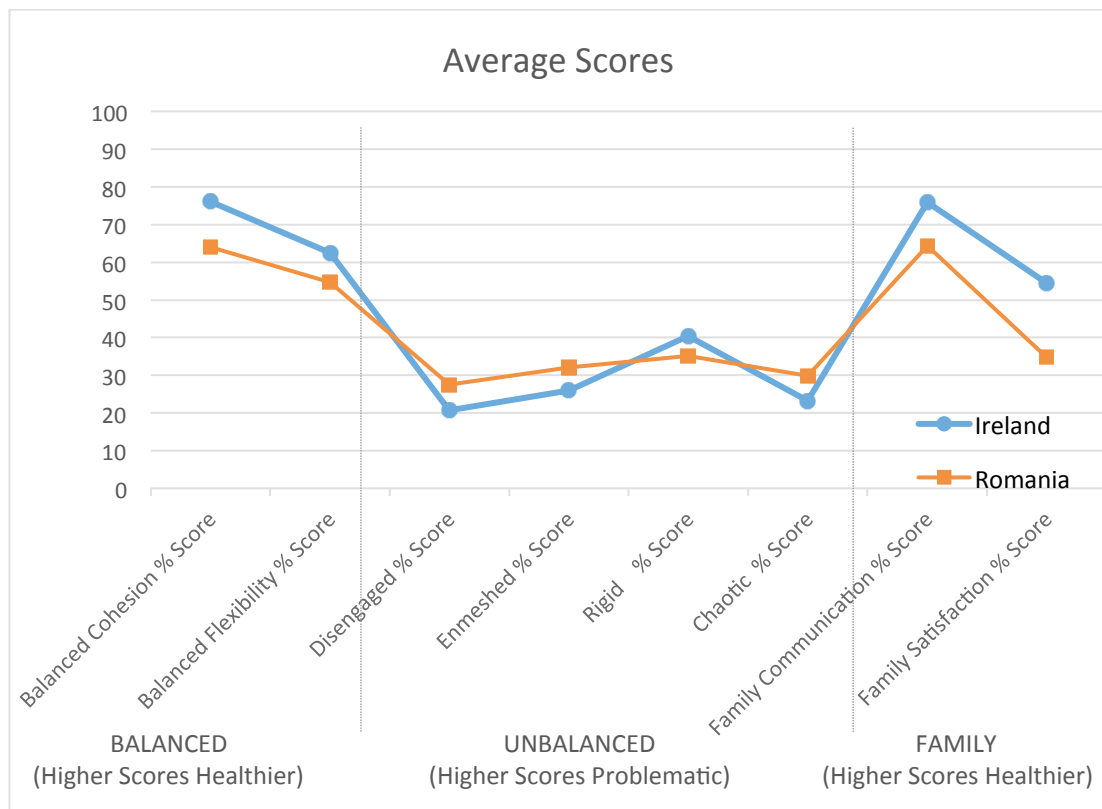


Figure 9-14. Average Faces IV Profile (Irish vs Romanian).

#### 9.2.5. Circumplex model

The cohesion dimension and flexibility dimension scores were used for plotting a location on the Circumplex Model. By using the dimension score on cohesion and flexibility, findings are located within the 25 cells of the Circumplex Model.

By plotting each individual onto the model, a visual overview of the number in each cell was obtained and a useful picture of the diversity of scores emerged.

Calculating the percentage in those three areas (Balanced area, mid-range area and unbalanced areas) of the Circumplex Model showed the percentage of healthy (balanced) versus unhealthy (unbalanced) aspects. Figure 9-15 and Figure 9-16 show the cohesion and flexibility dimension for each sample (Irish and Romanian families). In both samples, the results fell into the mid-range area and balanced area.

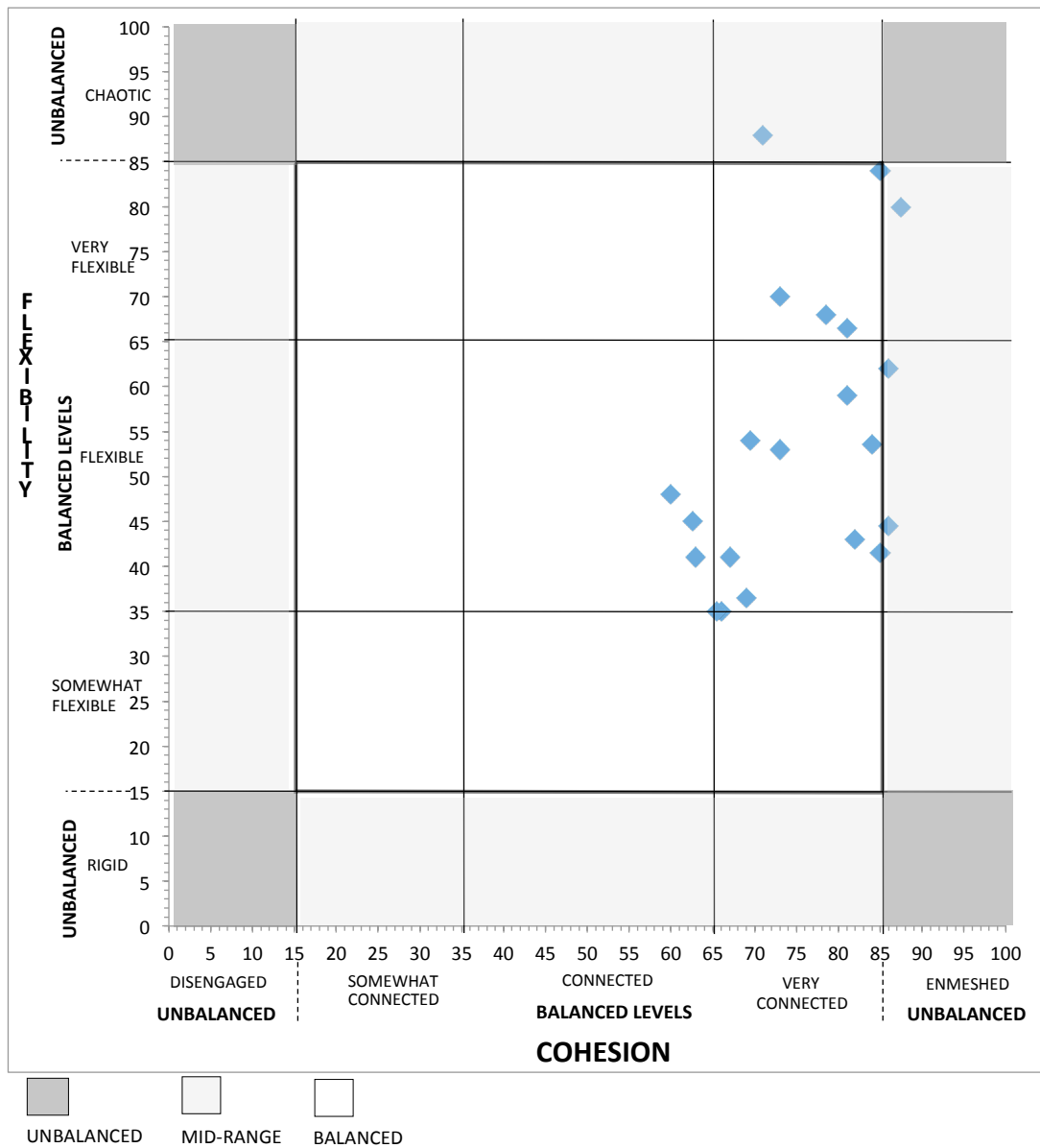


Figure 9-15. Faces IV Circumplex model for the Irish group.

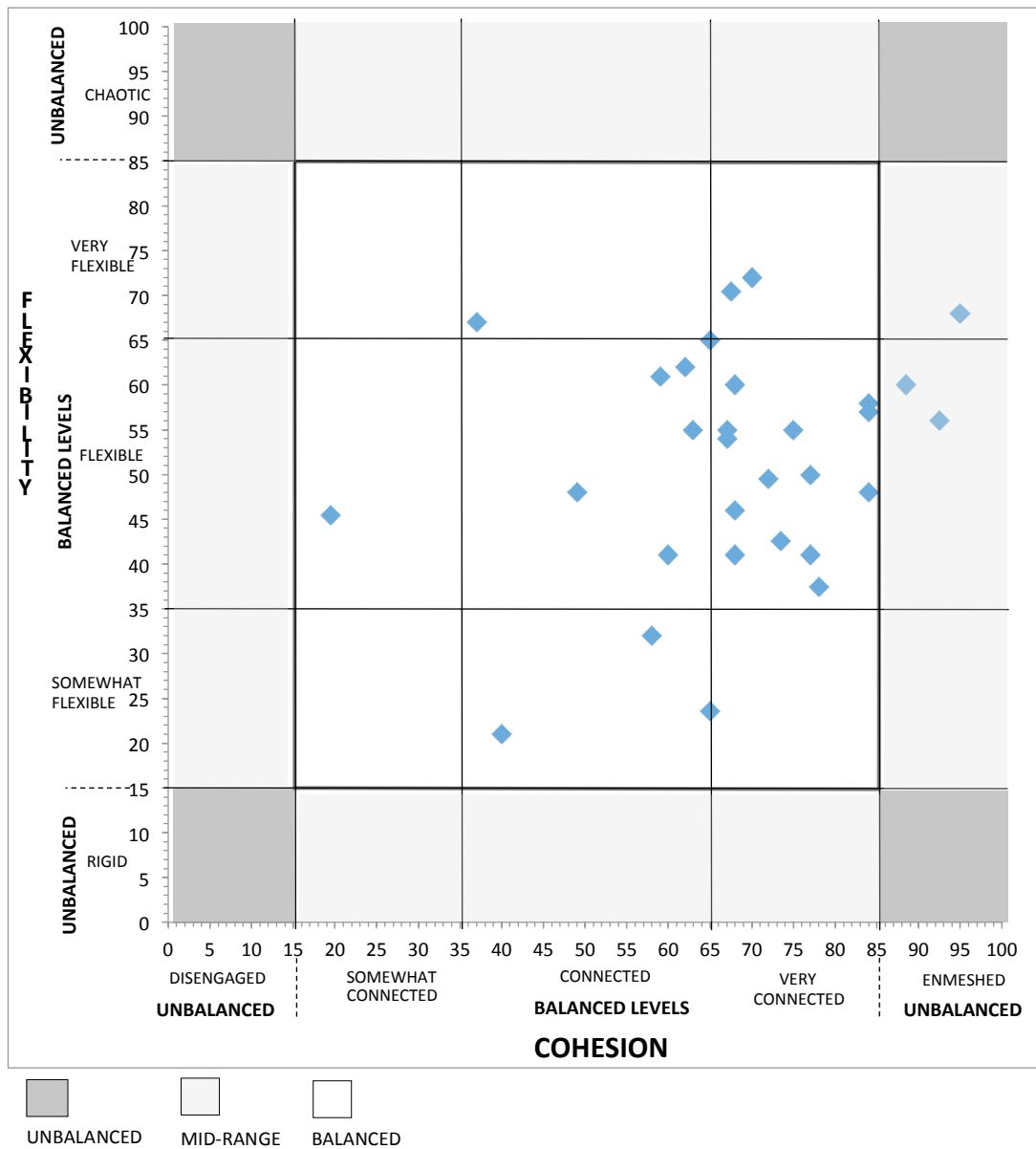


Figure 9-16. Faces IV Circumplex model for the Romanian group.

### 9.3. Hypothesis 1 – Differences in family functioning (FACES IV)

Aspects of family functioning (cohesion, flexibility, communication and satisfaction) in Irish families were different than family functioning in Romanian families. These data did not confirm the null hypothesis: *That there would be no difference between aspects of family functioning in Romanian and Irish families.*

#### 9.3.1. Balanced and unbalanced scores

In Table 9-28 , the balanced and unbalanced scores that resulted from FACES IV were averaged over the population of each group. In Table 9-29 the t–test results are displayed for equality of means between the two groups applied on the scores.

Table 9-28. Balanced and unbalanced scores: comparison of means.

	Country	Mean	Std. Deviation	Mean Difference	% Mean Difference	Significant?
Balanced cohesion % score	IE	76.08	9.160	11.017	14.4%	Yes
	RO	65.07	12.390			
Balanced flexibility % Score	IE	62.54	11.643	7.742	12.3%	Yes
	RO	54.80	10.682			
Disengaged % score	IE	20.71	11.312	-6.025	-29.1%	No
	RO	26.73	12.168			
Enmeshed % score	IE	26.04	19.477	-6.125	-23.5%	No
	RO	32.17	11.534			
Rigid % score	IE	40.38	16.086	3.575	8.8%	No
	RO	36.80	13.392			
Chaotic % score	IE	23.33	15.494	-6.667	-28.5%	No
	RO	30.00	13.633			

The t–test results showed that only for the balanced scores the difference was statistically significant ( $p < 0.05$ ): Balanced Cohesion Score and Balanced Flexibility Score. Even though there were differences between the means of the unbalanced scores, this difference was not statistically significant ( $p > 0.05$ ).

Table 9-29. Balanced and unbalanced scores: t-test results for equality of means.

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Balanced Cohesion % score	3.631	52	.001	11.017	3.034
Balanced Flexibility % score	2.543	52	.014	7.742	3.045
Disengaged % score	-1.865	52	.068	-6.025	3.231
Enmeshed % score	-1.361	35.5	.182	-6.125	4.499
Rigid % score	.891	52	.377	3.575	4.011
Chaotic % score	-1.681	52	.099	-6.667	3.967

The average cohesion score in the Romanian group was 65.07 while in the Irish group it was 76.08, with a difference of 11.017 (or 14.4%) between them. According to the t-test results shown in Table 9-29, this difference was statistically significant ( $p < 0.05$ ).

The average flexibility score in the Romanian group was 54.8 while in Irish group was 62.54, with a difference of 7.742 (or 12.3%) between them. According to the t-test results shown in Table 9-29, this difference was statistically significant ( $p < 0.05$ ).

### 9.3.2. Ratio scores

In Table 9-30 cohesion, flexibility and total ratio scores were compared as they resulted from FACES IV averaged over the population of each group. In Table 9-31 t-test results were included for equality of means between the two groups applied on the scores.

Table 9-30. Ratio scores: comparison of means.

	Country	Mean	Std. Deviation	Mean Difference	% Mean Difference	Significant?
Cohesion Ratio	IE	4.16	1.91	1.55	37.2%	Yes
	RO	2.6	1.3			
Flexibility Ratio	IE	2.29	1.12	.53	23.1%	Yes
	RO	1.75	.56			

Total Ratio	IE	3.22	1.39	1.04	32.3%	Yes
	RO	2.18	.87			

According to the t-test results the difference of means was statistically significant ( $p < 0.05$ ) for all ratio scores.

Table 9-31. Ratio scores: t-test results for equality of means.

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Cohesion Ratio	3.530	52	0.01	1.55	4.39
Flexibility Ratio	2.116	32.095	.042	.53	.25
Total Ratio	3.364	52	.001	1.04	.31

The average cohesion ratio score in the Romanian group was 2.6 while in the Irish group the average was 4.16, with a difference of 1.55 (or 37.2%) between them. According to the t-test results shown in Table 9-31, this difference was statistically significant ( $p < 0.05$ ).

The average flexibility ratio score in the Romanian group was 1.75 while in the Irish group it was 2.29, with a difference of 0.53 (or 23.1%) between them. According to the t-test results shown in Table 9-31, this difference was statistically significant ( $p < 0.05$ ).

Finally, the total ratio score in the Romanian group was 2.18 while in the Irish group it was 3.22, with a difference of 1.04 (or 32.3%) between them. According to the t-test results shown in Table 9-31, this difference was statistically significant ( $p < 0.05$ ).

Overall, according to the ratio scores, there was an important difference between the Irish and Romanian groups. The families in the Irish group had on average a more balanced family system in terms of both cohesion and flexibility than the families in the Romanian group.



### 9.3.3. Family communication and satisfaction

In Table 9-32 Family Communication and Satisfaction scores were compared as they resulted from FACES IV and averaged over the population of each group. In Table 9-33 t-test results were included for equality of means between the two groups applied on the scores.

Table 9-32. Family scores: comparison of means.

	Country	Mean	Std. Deviation	Mean Difference	% Mean Difference	Significant?
Family communication % score	IE	75.88	22.591	9.708	12.8%	No
	RO	66.17	23.314			
Family satisfaction % score	IE	54.58	29.050	19.150	35%	Yes
	RO	35.43	26.715			

The average communication score in the Romanian group was 66.17 while in Irish group it was 75.88, with a difference of 9.708 (12.8%) between them. However, according the t-test results shown in Table 9-33, this difference was not statistically significant ( $p > 0.05$ ).

Table 9-33. Family scores: t-test results for equality of means.

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Family communication % score	1.541	52	.129	9.708	6.298
	1.547	50.064	.128	9.708	6.276
Family satisfaction % score	2.518	52	.015	19.150	7.606
	2.494	47.431	.016	19.150	7.678

The average satisfaction score in the Romanian group was 35.43 while in Irish group it was 54.58, with a difference of 19.15 (35%) between them. As per t-test results shown in Table 9-33, this difference was statistically significant ( $p < 0.05$ ).

According to the results on family satisfaction scores, there was an important difference between the Irish and Romanian groups. The families in the Irish group

were in average more satisfied with their family life than the families in the Romanian group.

#### 9.4. Hypothesis 2 – Main family worries

Main family worries regarding their child when receiving the diagnosis in Ireland were different than family worries regarding their child when receiving a diagnosis in Romania. *This contradicted the null hypothesis, that there is no difference between Romanian and Irish families in terms of family worries.*

Question number 8 from the semi-structured interview was: What were your main worries when receiving the diagnosis? Main family worries were identified by parents and in relation to their child's diagnosis. In Figure 9-17 the frequency of the worries for each group are presented.

In the Irish group between 30% and 40% of the interviewed families were concerned with availability of the supporting services, future of their child, the fact that she/he may not be able to live independently and that she/he may not be able to talk, learn or improve.

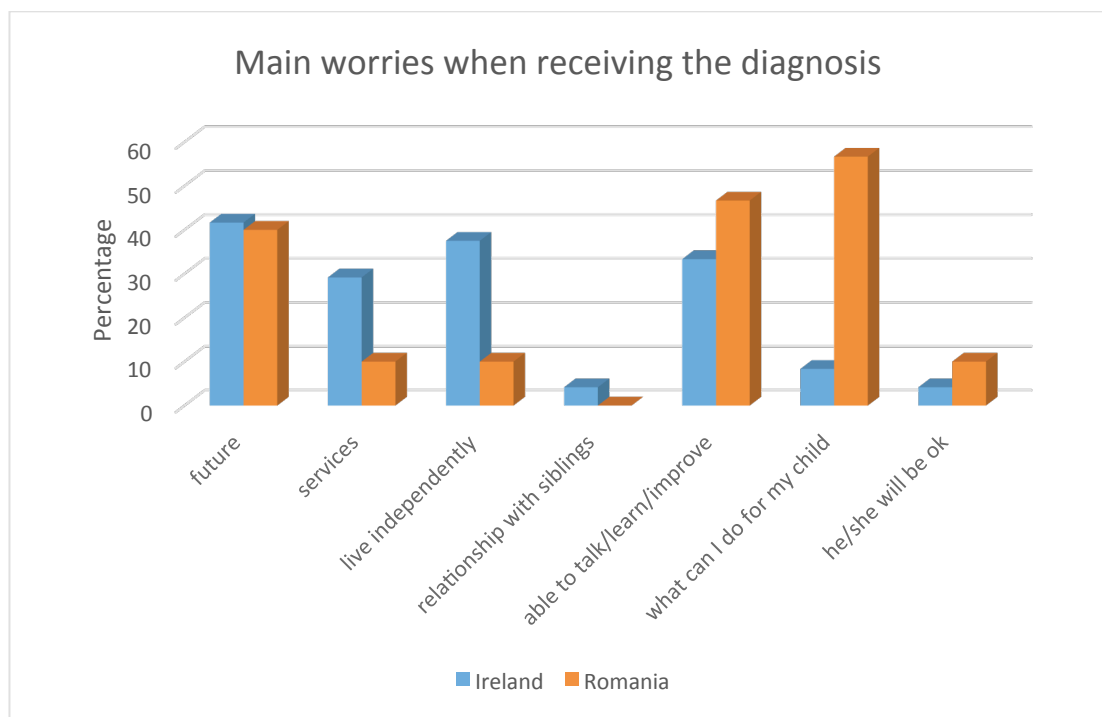


Figure 9-17. Main family worries when receiving a diagnosis (Irish vs Romanian).

The families in the Romanian group shared some of the concerns of the Irish families, like the future of their child and the ability to talk, learn or improve, but they were less concerned with the availability of the supporting services and the fact that she/he may not be able to live independently. Also, more than a half of the interviewed Romanian families were worried about what they can personally do to improve their child's condition.

Table 9-34. Main family worries: Irish vs Romanian (cross-tabulation).

Worries			Country		Total
			RO	IE	
future	Count		12	10	22
	% within worries		54.5%	45.5%	
	% within country		40.0%	41.7%	
services	Count		3	7	10
	% within worries		30.0%	70.0%	
	% within country		10.0%	29.2%	
live independently	Count		3	9	12
	% within worries		25.0%	75.0%	
	% within country		10.0%	37.5%	
relationship with siblings	Count		0	1	1
	% within worries		0.0%	100.0%	
	% within country		0.0%	4.2%	
able to talk/learn/improve	Count		14	8	22
	% within Worries		63.6%	36.4%	
	% within Country		46.7%	33.3%	
what can I do for my child	Count		17	2	19
	% within worries		89.5%	10.5%	
	% within country		56.7%	8.3%	
he/she will be ok	Count		3	1	4
	% within worries		75.0%	25.0%	
	% within country		10.0%	4.2%	
Count	30	24	54		

The statistical significance of the difference of each response was calculated using the Pearson Chi-Square. For each main worry identified we compared the nominal

variable representing the country (Ireland or Romanian) with the dichotomy variable representing the related response. The results of the test are shown in Table 9-35.

Table 9-35. Pearson Chi-square results: main family worries (Irish vs Romanian)

Worries	Value	df	Asymp. Sig. (2-sided)
future	.015a	1	.901
services	3.246	1	.072
live independently	5.834	1	.016
relationship with siblings	1.274	1	.259
able to talk/learn/improve	.982	1	.322
what can I do for my child	13.658	1	.000
he/she will be ok	.662	1	.416

The worries where the difference in responses between the two groups were statistical significant are ‘live independently’ and ‘what can I do for my child’.

### 9.5. Hypothesis 3 – Level of involvement

Irish families showed level of involvement in their child's development differently than Romanian families. *Thus the null hypothesis, i.e. that there would be no difference between Romanian and Irish families regarding level of involvement in their child's development was not supported.*

An involvement score was calculated for each family based on the seven interview questions and responses (Table 9-38):

- +1 ratio score if they discussed the child's diagnosis with family members, extended family, friends or professionals (ratio score between 0 and 1 based on how many answers they gave)
- +1 if they discussed the child's diagnosis with other parents who have children with ASD
- + ratio score if they were aware of types of services and therapies available for children with ASD (ratio score between 0 and 1 based on how many answers they gave)
- +1 if they mentioned constant care and supervision as part of their daily routine with the child
- +1 if they mentioned continuation of therapies at home as part of their daily routine with the child
- +1 if they knew something about children with ASD from their own country
- +1 if they knew something about children with ASD from the other country
- +1 if they responded yes when asked if they have any questions. In the Irish group there were only two families who asked questions at the end of the interview, while in the Romanian group all families had some questions at the end. The main questions that the Romanian group asked were in relation to research, ABA, services in Ireland and around the world.

The resulting score was a value between 0 and 8, with higher value indicating a higher level of involvement. The involvement scores for both Irish and Romanian groups are shown in Figure 9-18 for each group. There was a visible difference in these distributions. In the Irish group, most of the values were in the range of

between 2 and 4, while in the Romanian group the range of most values were between 5 and 7.

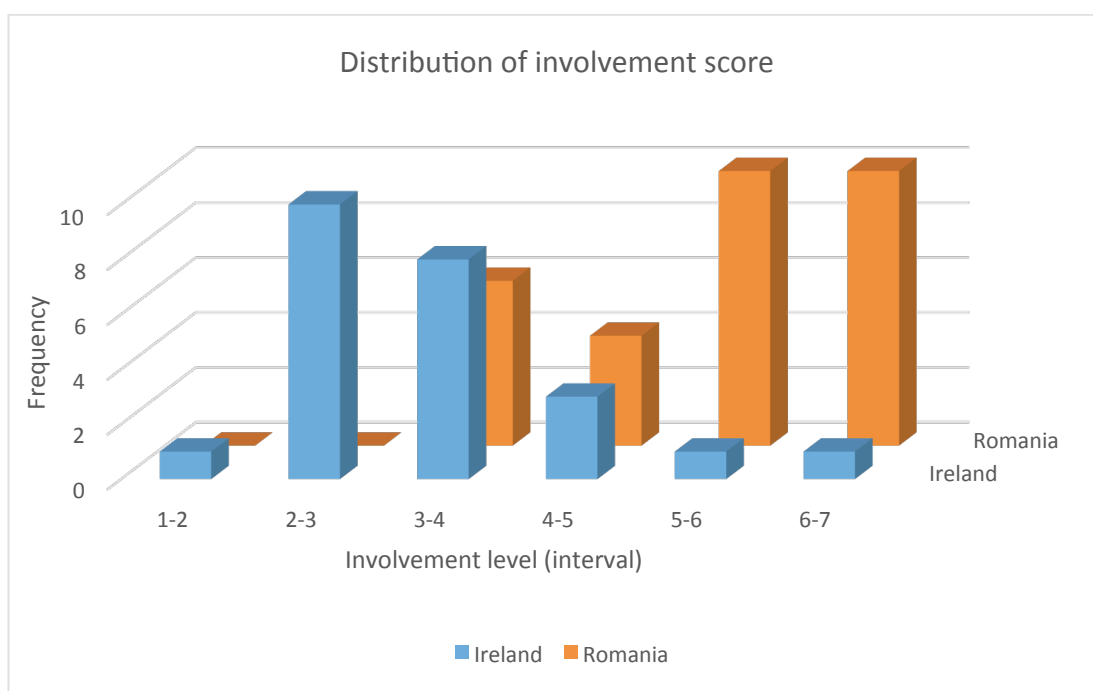


Figure 9-18. Distribution of involvement score for Irish and Romanian groups.

This difference was also reflected in the mean score for the two groups. The mean score for the Irish group was 3.25, while the mean score for the Romanian group was 5.52, a difference of 2.277. In average the involvement score in the Romanian group was 70% higher when compared with the score of the Irish group (Table 9-36).

Table 9-36. Involvement score: comparison of means.

	Country	Mean	Std. Deviation	Mean Difference	% Mean Difference	Significant?
Involvement score	IE	3.2515	1.14501	-2.277	-70%	Yes
	RO	5.5286	1.11521			

According to the t-test results shown in Table 9-37, this difference was statistically significant ( $p < 0.05$ ).

Table 9-37. Involvement score: t-test results for equality of means.

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Involvement score	-7.368	52	.000	-2.27708	.30905

In average, the Romanian families had a higher level of involvement when compared to Irish families.

The questions used for this hypothesis were based on the assumption that the level of family involvement can be different in two different cultures. The differences in legislation, assessment, history, services, described for each country in Chapter 4 and Chapter 5 conducted to the present assumption. Thus, the questions were grouped based on the purpose of hypothesis. Only open questions were used for this purpose in order to capture many aspects of family involvement. Table 9-38 shows the details of each question that contributed to the overall involvement score.

Table 9-38. Level of involvement: questions and answers.

Question	Response	Ireland (%)	Romania (%)
Who did you discuss your child's diagnosis with	family members	37.5	33.3
	extended family	12.5	20
	friends	16.6	0
	everybody	45.8	66.6
	professionals	16.6	0
	nobody	8.3	0
Discuss with other parents who have children with ASD	yes	62.5	70
	no	37.5	30
What type of services for children with ASD are you aware of	physiotherapy	20.8	83.3
	occupational therapy	50	83.3
	speech and language therapy	62.5	86.6
	play therapy	16.6	73.3
	early intervention services	20.8	76.6
	therapeutic listening	12.5	66.6
	PECS	29.1	73.3
	ABA	20.8	83.3
	music therapy	0	86.6
	horse riding + dogs	8.3	73.3
	nothing	16.6	10
	sensor integration	4.1	66.6
	art therapy	0	70
	TEACCH	0	70
	medication	4.1	73.3
Describe a regular day with your child	constant care and supervision	66.6	10
	lot of stress	41.6	20
	continue therapies at home	25	73.3
	free activities	50	90
Do you know something about children with ASD	yes	33.3	60



from your country	no	66.6	40
Do you know something about children with ASD from the other country (Romania/Ireland)	yes	45.8	83.3
	no	54.1	16.6
Do you have any questions	yes	8.3	100
	no	91.6	0

The family's opportunity to discuss their child's diagnosis with different people was explored. The answers are displayed in Figure 9-19 and include family members, extended family, friends, everybody, professionals and nobody. The Romanian group discussed their child's diagnosis with everybody (66.65), while in the Irish group only 45.8% had discussed their child's diagnosis widely. Both groups discussed their child's diagnosis with family members and extended family.

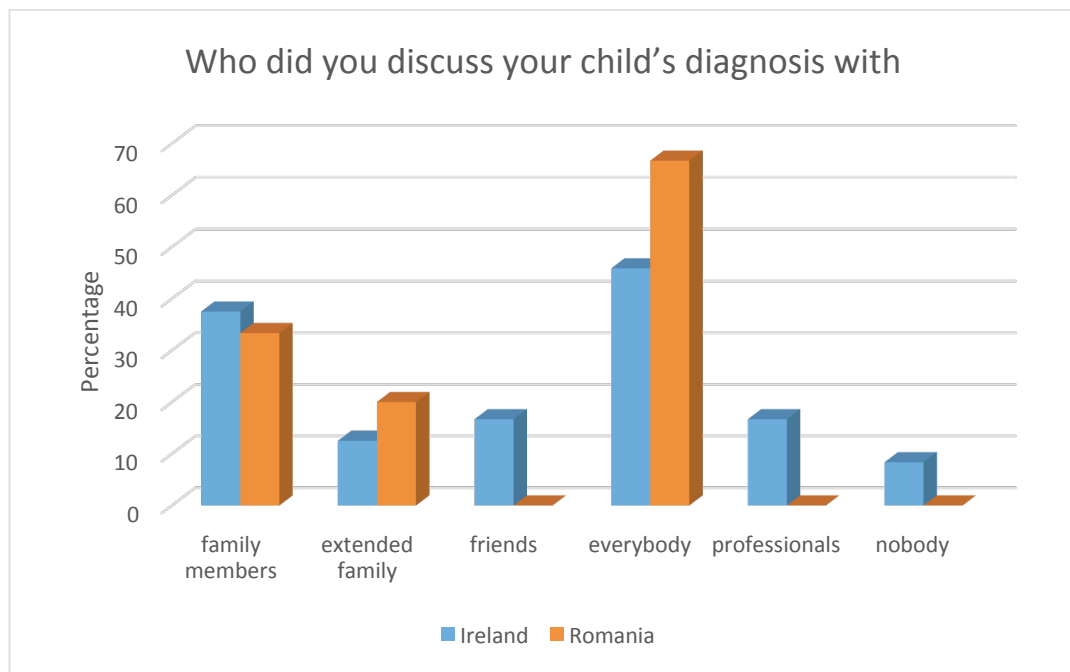


Figure 9-19. Discussion of child's diagnosis (Irish vs Romanian).

The family's opportunity to discuss their child's diagnosis with other parents who have children with ASD was important (Figure 9-20). Both groups discussed their child's diagnosis with other families who have children with ASD (70% Romanian group and 62.5% Irish group).

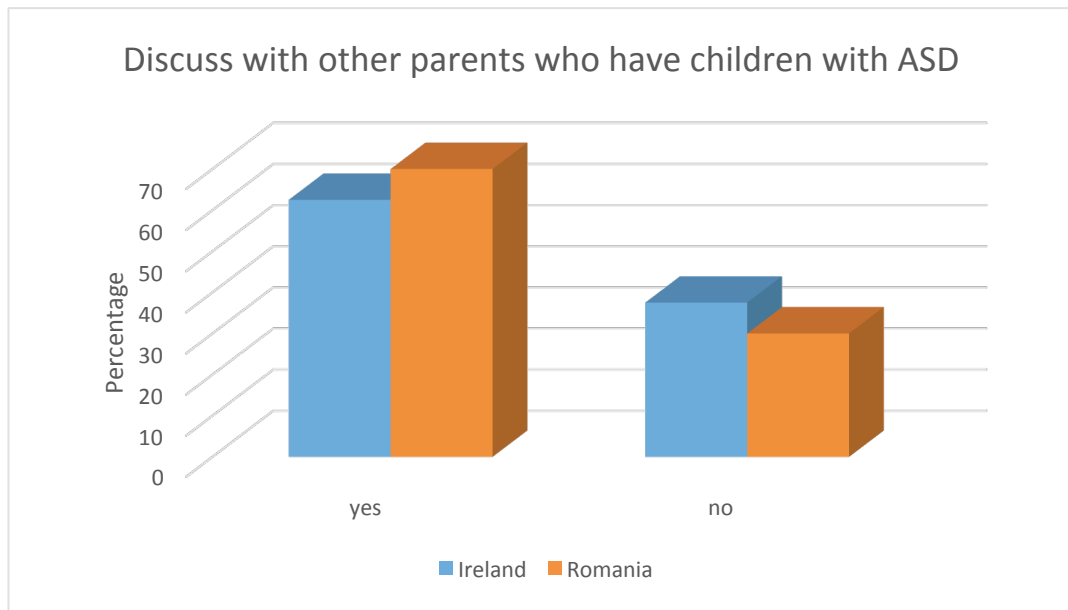


Figure 9-20. Discussion with other parents who have children with ASD (Irish vs Romanian).

The next question asked about family's knowledge in relation to type of services/therapies that they were aware of (Figure 9-21). Parents' answers were: physiotherapy, occupational therapy, speech and language therapy, early intervention, therapeutic listening, PECS, ABA, music therapy, horse-riding and dogs, nothing, sensory integration, art therapy, TEACCH, medication.

The Romanian group described a lot of services and therapies for children with ASD (between 66.6% and 86.6%). They mentioned that their children attend almost all these therapies. Only 10% state that they do not have information about therapies.

In the Irish group, a high percentage mentioned speech and language therapy (62.5%). They mentioned that their child attended this form of therapy or they were on the waiting list for it. Nobody mentioned about music therapy, TEACCH and art therapy. Only 16.6% state that they do not have information about therapies.

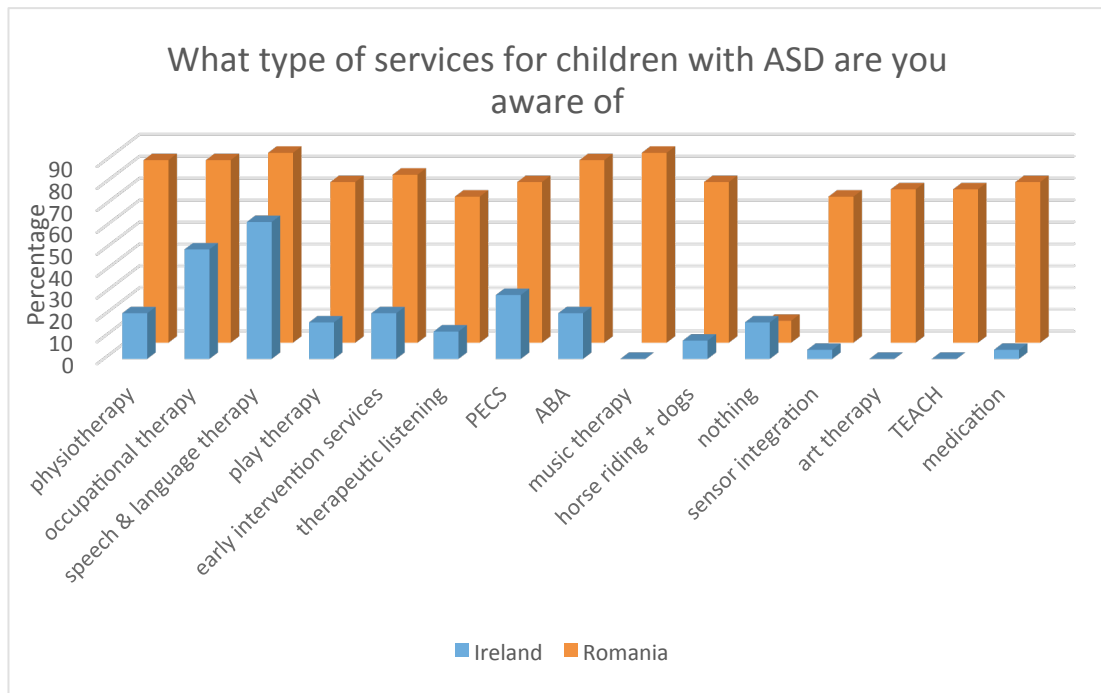


Figure 9-21. Knowledge about type of therapies and services available for children with ASD (Irish vs Romanian).

When parents were asked to describe a regular day with their child, the answers were grouped as follows: constant care and supervision; a lot of stress; we continue therapies at home; and free activities (Figure 9-22). A high percentage of the Romanian group reported that they did free activities (90%) and continue the therapies at home with their child (73.3%). Stress (20%) and constant care and supervision (10%) was mentioned by a small percentage of parents.

In the Irish group, the majority described a regular day with a lot of stress (41.6%), free activities (50%) and constant care and supervision (66.6%). Only 25% of families continued the therapies at home with their child.

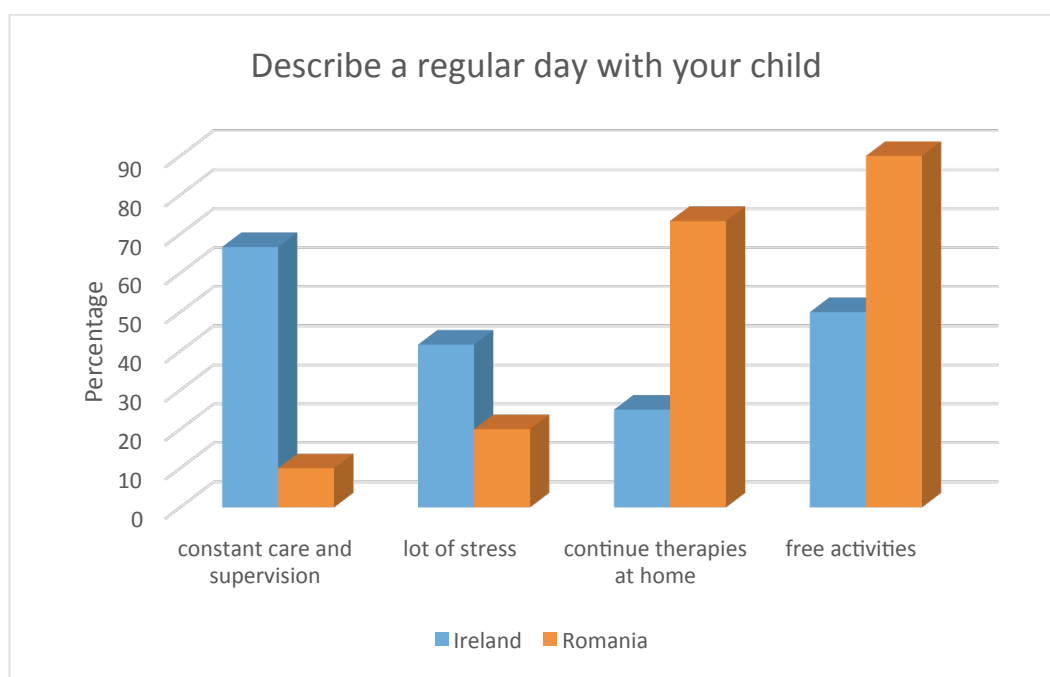


Figure 9-22. Daily routine with the child (Irish vs Romanian).

The next two questions were included to emphasize parents' level of involvement by asking about their knowledge about children with autism in both countries. Figure 9-23 and Figure 9-24 include the distribution of parents' level of knowledge about children with ASD from their own country and from the other country.

Irish families had different views/knowledge in relation to children with ASD from both countries (Ireland and Romania) than Romanian families.

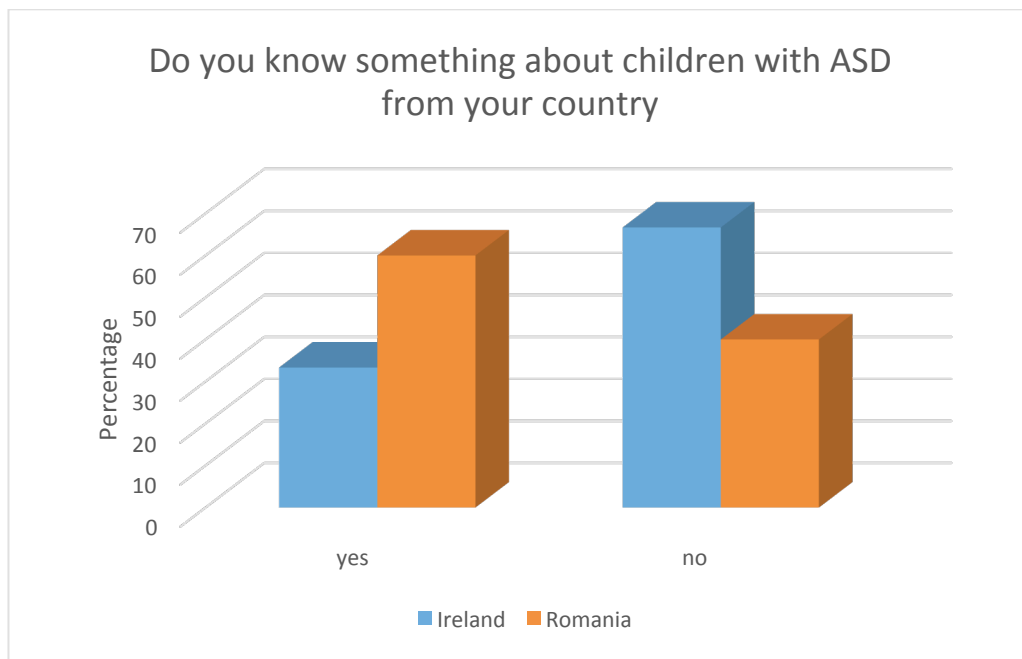


Figure 9-23. Level of knowledge of parents about children with ASD from their own country (Irish vs Romanian).

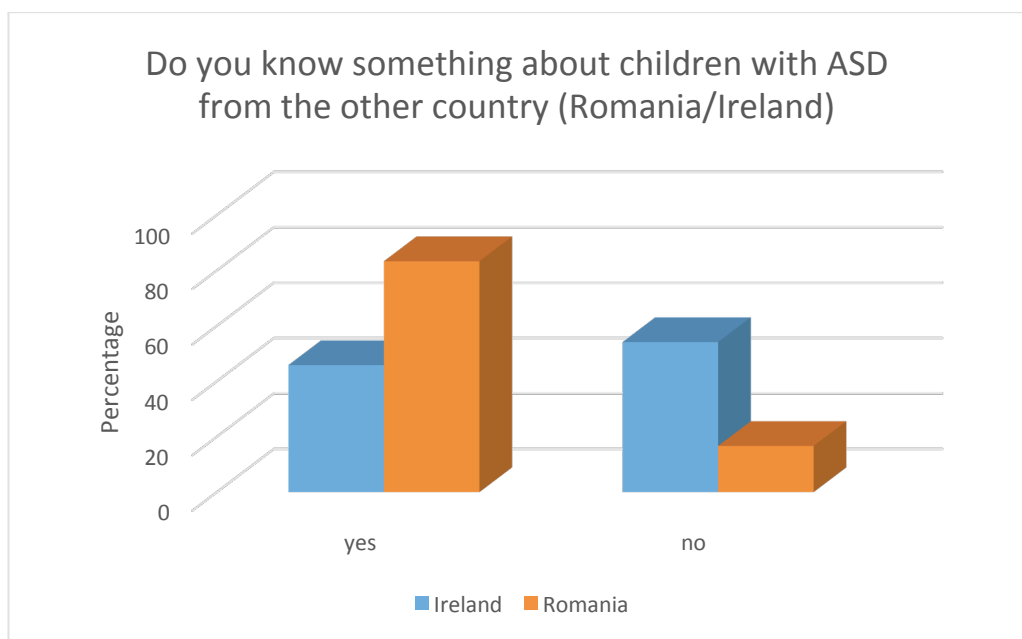


Figure 9-24. Level of knowledge of parents about children with ASD from the other country (Romania/Ireland).

Families in both groups were asked whether they know anything about children with autism in both their own country and the other country (questions number 17 and 18, Appendix 3). The questions were: What do you know about children diagnosed with

autism in Romania? and What do you know about children diagnosed with autism in Ireland? Figure 9-25 shows the answers (*yes* and *no*) for the Irish group.

In the Irish group, 46% of families had information about children with ASD in Ireland, while 54% said that do not have information about children with ASD in Ireland. Families who mentioned that they have information about children with ASD in Ireland stated: “The TV and radio programmes show many cases of autism. We read books. I found useful information on Internet. The psychologist told us about autism ... I only know about the Early Intervention Team in Lucan (Dublin West).” They also mentioned that access to services was different from county to county and stated that now there was more awareness about ASD in Ireland because of increased coverage by the media. Families also mentioned that now people generally talked more about ASD.

Families who mentioned that they do not have information about children with ASD in Ireland stated: “I do not have information. Nothing. I did not read books. Nobody told us about autism. The doctor said my child has autism and did not explain me what is it.”

As many as 67% of Irish families mentioned that they do not have any information about children with ASD from Romania. Their answers were mainly “No. I do not have any information about children with autism from Romania. I do not know anything about Romania.” The 33% of Irish families declared that they have some information about children with ASD from Romania. Their answers were: “I know about Romanian gypsies ... they stay on O’Connell Street. Probably services are worse than here. Romania is a poor country. I think Romania has no services for children with autism. I now about Ceausescu and communism ... I saw a TV programme about orphanages from Romania. Romania is an isolated country.”

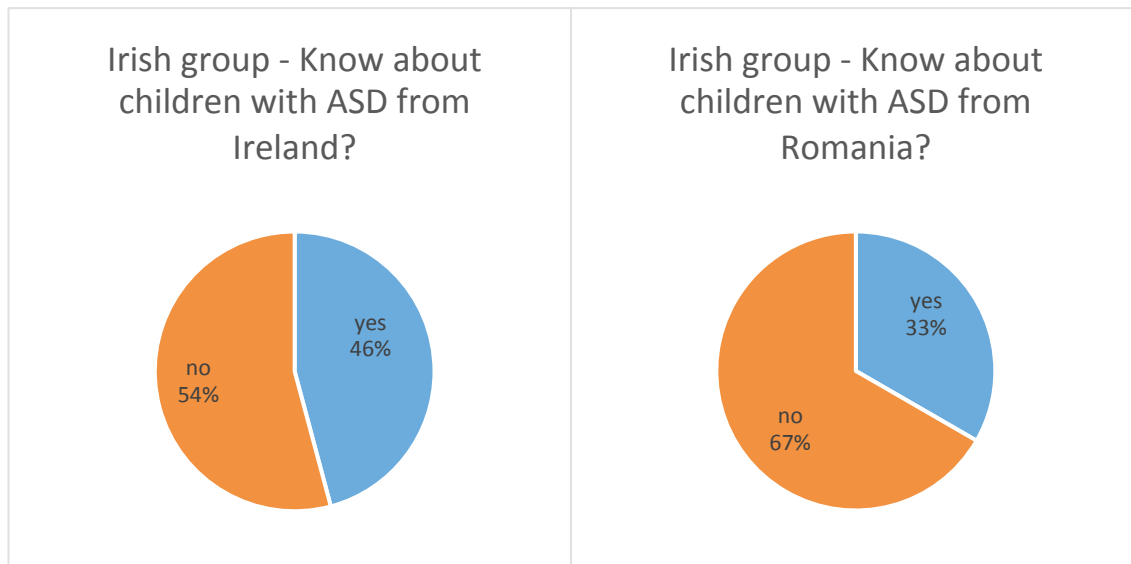


Figure 9-25. ASD awareness in the Irish group.

On the other hand, 83% of Romanian families stated that they had information about children with autism in their own country. They mentioned that there was a trend to favour ABA-based interventions among parents and service-providers, increased interest in research work on autism, financial difficulties and a need for more ABA-based services. Also, 60% of Romanian families knew something about children with ASD from Ireland and they mentioned that they thought there were better services in Ireland. Figure 9-26 shows the answers (*yes* and *no* in percentage) for the Romanian group.

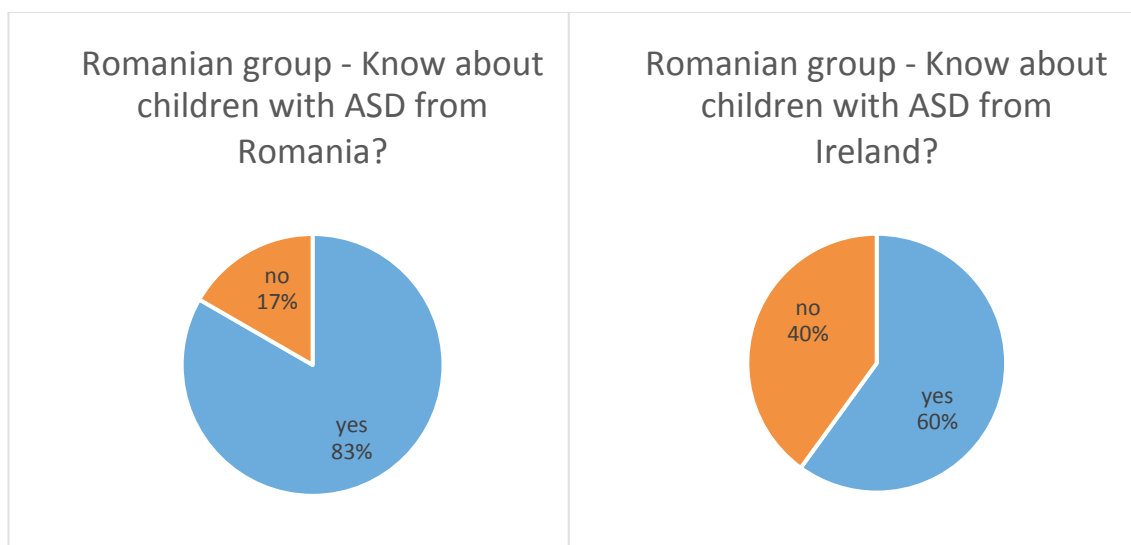


Figure 9-26. ASD awareness in the Romanian group.

Another question used to underline parent's level of involvement was the last question in the semi-structured interview: *Do you have any questions?* All participants in the Romanian group (100%) asked questions about this study, ASD, ABA, research in ASD and other therapies. Only 8.3% in the Irish group asked questions about ASD and research in ASD.



#### 9.6. Hypothesis 4 – Role of the mother and father

Irish families were found to have a different perspective about the role of the mother/father in raising a child with ASD than Romanian families, *thus not confirming the null hypothesis that there is no difference between Romanian and Irish families regarding the role of mother/father in raising a child with ASD.*

We asked the families in both groups what they think the roles of mother and father were in raising a child with autism.

In the Irish group, between 20% and 30% mentioned the role of mother as being the same as father, to offer emotional support and to stay at home with the children. Approximately, 10–20% of Irish families believed that the role of mother is to take care of the financial aspects. Between 30–40% considered that the role of mother is to control everything. In the Romanian group, between 60–70% considered the role of mother as being the same as the role of the father, while 30–40% thought that mother should do everything. Only 0–10% considered that mother should stay at home with the children and referred to emotional support (see Figure 9-27).

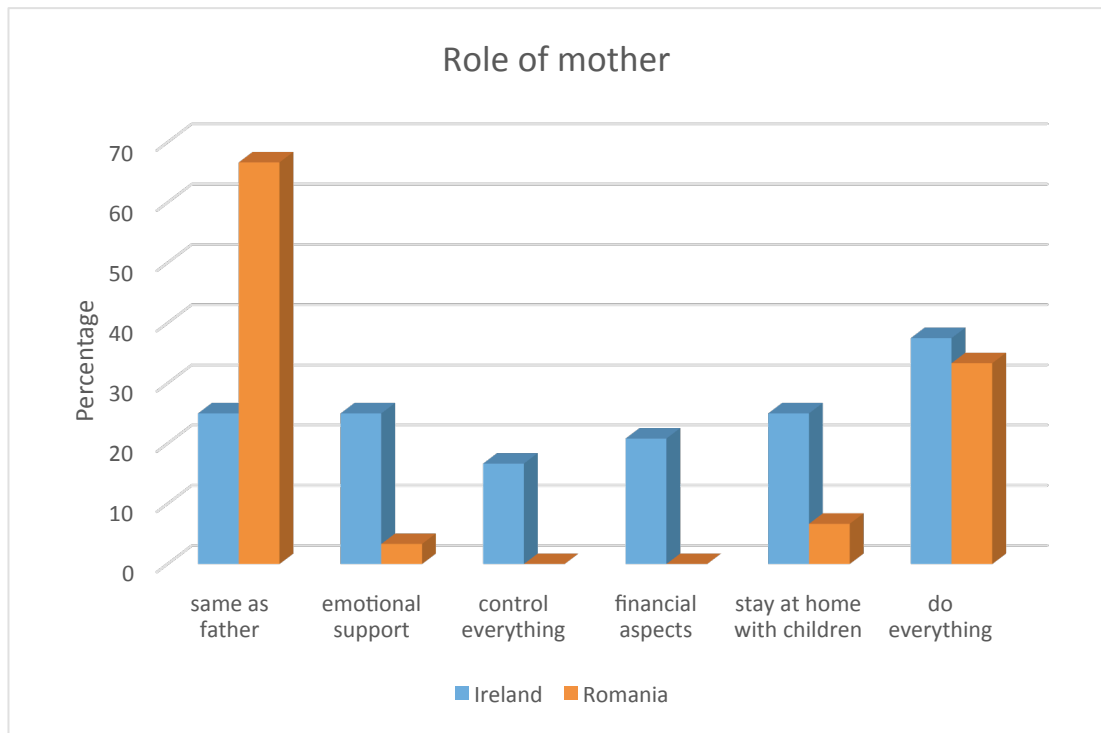


Figure 9-27. Perceived role of the mother (Irish vs Romanian).

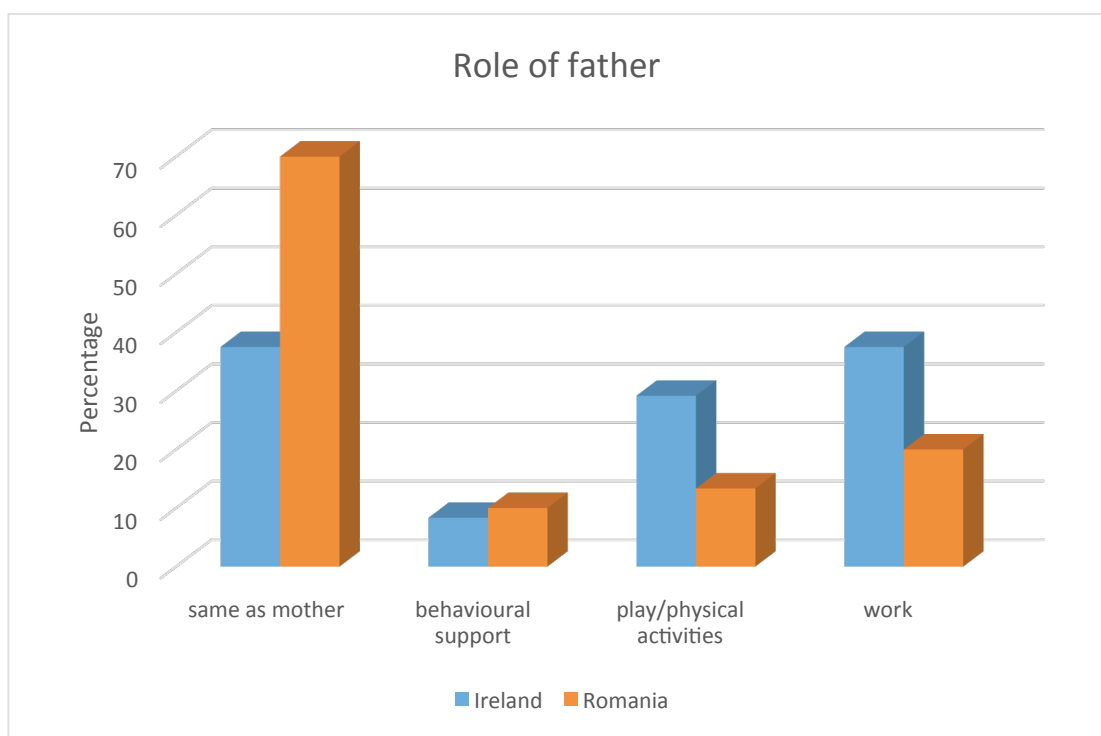


Figure 9-28. Perceived role of the father (Irish vs Romanian).

In the Irish group, between 30–40% considered the role of father as being the same as the mother and to work. Between 20–30% believed that the role of father is to play

with and do physical activities with children. Only 0–10% considered the role of father as being in behavioural support (Figure 9-28). In the Romanian group, 60–70% considered the role of father as being the same as the mother, 10–20% referred to work and carrying out play/physical activities with their children. Only 0–10% mentioned behavioural support.

Table 9-39. Role of mother: Irish vs Romanian (cross-tabulation).

Role of mother		Country		Total
		Romania	Ireland	
the same as father	Count	20	6	26
	% within Role of mother	76.9%	23.1%	
	% within country	66.7%	25.0%	
emotional support	Count	1	6	7
	% within Role of mother	14.3%	85.7%	
	% within country	3.3%	25.0%	
to control everything	Count	0	4	4
	% within Role of mother	0.0%	100.0%	
	% within country	0.0%	16.7%	
financial aspects	Count	0	5	5
	% within Role of mother	0.0%	100.0%	
	% within country	0.0%	20.8%	
to stay at home with children	Count	2	6	8
	% within Role of mother	25.0%	75.0%	
	% within Country	6.7%	25.0%	
to do everything	Count	10	9	19
	% within Role of mother	52.6%	47.4%	
	% within country	33.3%	37.5%	
Total	Count	30	24	54

The statistical significance of the difference of each response was calculated using the Pearson chi-square. For each role identified, we compared the nominal variable representing the country (Ireland or Romanian) with the dichotomy variable representing the related response. The results of the test are shown in Table 9-40.

Table 9-40. Pearson chi-square results: role of mother (Irish vs Romanian).

Role of mother	Value	df	Asymp. Sig. (2-sided)
the same as father	9.272 <sup>a</sup>	1	.002
emotional support	5.548 <sup>a</sup>	1	.019
to control everything	5.400 <sup>a</sup>	1	.020
financial aspects	6.888 <sup>a</sup>	1	.009
to stay at home with children	3.551 <sup>a</sup>	1	.060
to do everything	.102 <sup>a</sup>	1	.750

The mothers' roles where the difference in responses between the two groups were statistical significant were: "the same as father", "emotional support", "to control everything", "financial aspects".

Table 9-41. Role of the father: Irish vs Romanian (cross-tabulation).

Role of father		Country		Total
		Romania	Ireland	
the same as mother	Count	21	9	30
	% within Role of father	70.0%	30.0%	
	% within Country	70.0%	37.5%	
behavioural support	Count	3	2	5
	% within Role of father	60.0%	40.0%	
	% within Country	10.0%	8.3%	
play/physical activities	Count	4	7	11
	% within Role of father	36.4%	63.6%	
	% within Country	13.3%	29.2%	
to work	Count	6	9	15
	% within Role of father	40.0%	60.0%	
	% within Country	20.0%	37.5%	
Total	Count	30	24	54

Table 9-42 Pearson chi-square results: role of the father (Irish vs Romanian).

Role of father	Value	df	Asymp. Sig. (2-sided)
the same as mother	5.704 <sup>a</sup>	1	.017
behavioural support	.044 <sup>a</sup>	1	.834
play/physical activities	2.061 <sup>a</sup>	1	.151

to work	2.035 <sup>a</sup>	1	.154
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The fathers' roles where the difference in responses between the two groups were statistical significant was: "the same as mother".

### 9.7. Hypothesis 5 – Experience of diagnosis

The experience of the family when their child received their diagnosis in Ireland was different to the experience of families when their child received diagnosis in Romania, thus *not confirming the null hypothesis, that there is no difference between Romanian and Irish families in terms of family experience.*

For this hypothesis and in order to capture family's experience during the diagnostic process, 10 questions were included. The 10 questions used for this hypothesis were based on the assumption that family experience can be different in two different cultures. The differences in legislation, assessment, history, services, described for each country in Chapter 4 and Chapter 5 contributed to the present assumption. Thus, the questions were grouped based on the purpose of hypothesis. Only open questions were used for this purpose in order to capture the many aspects of family experience during the diagnostic process.

The negative experience score was calculated for each family based on the following 8 interview questions and responses:

- +1 if changes in family life include one or more of: more stress, separation, quit work
- +1 if the family experience and feelings described include one or more of: denial, anger, blame, sadness, worried about future
- +1 if first thoughts after diagnosis include one or more of: why, sadness, not able to think, panic
- +1 if experience in accessing services was negative
- +1 if experience in accessing educational services was negative
- +1 if experience of grandparents in dealing with diagnosis was one or more of: stress, denial, sadness, shock, does not understand
- +1 if the diagnosis was affecting the relationship between parents with one or more of: more stress, conflict, separation
- +1 if the diagnosis was affecting the relationship between brothers and sisters with one or more of: conflict/stress, confusion

The resulting score was a value between 0 and 8, with a high value indicating a higher level of negative experience.

The positive experience score for each family based on the following interview questions and responses:

- +1 if changes in family life include one or more of: more supportive, no changes or focus on child
- +1 if first thoughts after diagnosis include one or more of: child's future, need for information, what's next
- +1 if experience in accessing services was positive
- +1 if experience in accessing educational services was positive
- +1 if experience of grandparents in dealing with diagnosis was focus to help
- +1 if the diagnosis was affecting the relationship between parents by making it more stronger and closer
- +1 if the diagnosis was affecting the relationship between brothers and sisters by making them more closer and more involved
- +1 if the diagnosis was affecting the relationship between family and grandparents/extended family by focusing to provide support or more closure

The resulting score was a value between 0 and 8, with high value indicating a higher level of positive experience.

Finally, both negative and positive experience scores were combined into an experience score, by subtracting the negative experience score from the positive experience score. The resulted score has value between -8 and +8, with lower (negative) values indicating a more negative experience, while the higher (positive) values indicate a more positive experience.

The distributions of the experience score for both Irish and Romanian groups are shown in Figure 9-29 for each group. There was a visible difference in these distributions. In the Irish group, most of the values were in the range between -5 and -1, while in the Romanian group the range of most values were between -1 and 4.

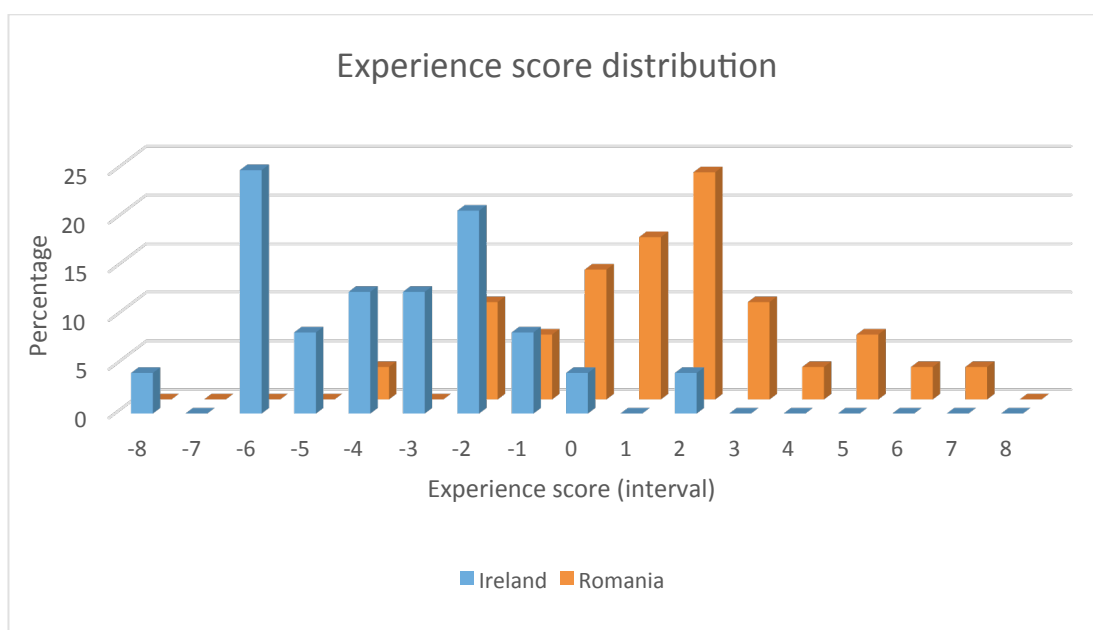


Figure 9-29. Experience score distribution for Irish and Romanian groups

This difference was also reflected in the mean score for the two groups (Table 9-43). The mean score for the Irish group was  $-3.54$ , indicating a completely negative experience overall. On the other side, the mean score for the Romanian group was  $1.43$  ( $4.975$  higher than for the Irish Group), pointing to a more neutral experience, rather than negative.

Table 9-43. Experience score: comparison of means.

	Country	Mean	Std. Deviation	Mean Difference	Significant?
Experience score	IE	-3.54	2.377	-4.975	Yes
	RO	1.43	2.487		

According to the t-test results in Table 9-44, the difference in the experience score was statistically significant ( $p < 0.05$ ).

Table 9-44. Experience score: t-test results for equality of means.

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Experience score	-7.448	52	.000	-4.975	.668

Overall, the Romanian families had a better diagnostic experience when compared to Irish families. Details of each question that contributed to the overall experience score are shown in Table 9-45.



Table 9-45. Questions and responses related to family experience.

Question	Response	Ireland (%)	Romania (%)
Changes in family life	More stress	66.6	66.6
	Changes in all aspects of family life	58.3	36.6
	Separation	16.6	3.3
	More supportive	12.5	10
	Quit work	4.1	3.3
	No changes	12.5	6.6
	Focus on child with ASD	37.5	36.6
First thoughts after diagnosis	why	37.5	43.3
	child's future	58.3	23.3
	sadness	25	23.3
	not able to think	4.1	10
	panic	12.5	26.6
	need for information	33.3	46.6
	what's next	33.3	23.3
Family experience and feelings	shock	50	36.6
	not able to describe feelings	25	50
	denial	29.1	73.3
	anger	25	13.3
	blame	16.6	10
	sadness	66.6	33.3
	worried about future and services	12.5	20
Experience in accessing services	positive	0	90
	negative	100	6.6
Experience in accessing educational services	positive	8.3	86.6
	negative	91.6	10
Experience of grandparents in dealing with diagnosis	stress	33.3	23.3
	denial	20.8	23.3
	sadness	45.8	16.6
	shock	37.5	16.6
	does not understand	37.5	13.3
	no involvement/ they don't know	16.6	16.6
	focus to help	0	53.3
Diagnosis affecting the relationship between parents	more stress	62.5	60
	conflict	33.3	33.3
	separation	29.1	0
	more stronger/closer	33.3	46.6
Diagnosis affecting the relationship between brothers and sisters	conflict/stress	50	6.6
	confusion	33.3	6.6
	did not affect them	8.3	13.3
	more closer, more involved	20.8	10
	no siblings	20.8	70
Diagnosis affecting the relationship between family and grandparents	focus to provide support	54.1	53.3
	more closeness	25	0
	did not affect them	20.8	16.6
	same relationship	12.5	43.3

The answers to the first question related to changes in family life included: more stress, changes in all aspects of family life, separation, more supportive, quit work, no changes, focus on child with ASD (Figure 9-30). All questions were open questions.

Similar changes in family life (66.6%) were observed in both groups in relation to more stress experienced since they received the diagnosis. Significant changes were observed in both groups regarding focus on child with ASD (37.5% in the Irish group and 36.6% in the Romanian group) and changes in all aspects of family life (58.3% in the Irish group and 36.6% in the Romanian group). Separation of couples (16.6%) was observed as a change in the Irish group.

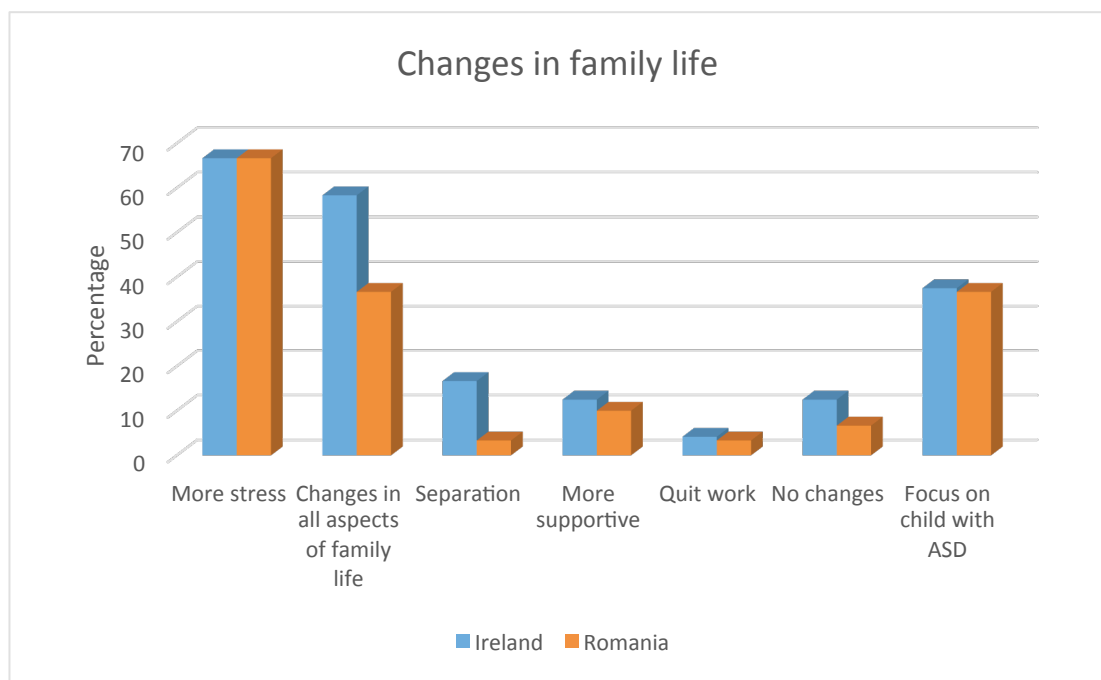


Figure 9-30. Changes in family life after diagnosis (Irish vs Romanian).

Answers to the next question which included family's feelings regarding child's diagnosis included: shock, denial, anger, blame, sadness, worries about future and services and being unable to describe their feelings (Figure 9-31).

In the Romanian group, family experienced more denial (73.3%) in comparison to the Irish group (29.1%), sadness (33.3%) and shock (36.6%) were also experienced by the Romanian families. Half (50%) were not able to describe their feelings and 20% were worried about their child's future and services.

In the Irish group, 66.6% experienced sadness, 25% anger, 50% shock, 29.1% denial, and blame 16.6%. Only 25% were not able to describe their feelings and 12.5% were worried about their child's future and services.

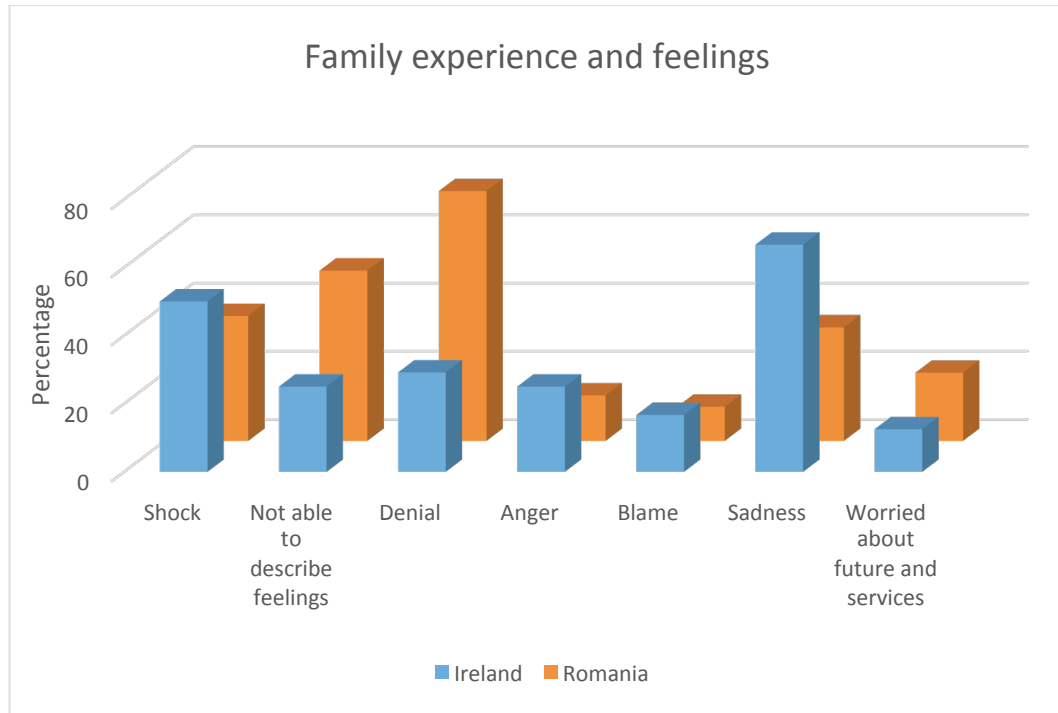


Figure 9-31. Family feelings after diagnosis (Irish vs Romanian).

Answers to the next question which included family's first thoughts when received the diagnosis included: what's next, need for information, panic, not able to think, sadness, child's future, why (Figure 9-32).

In the Irish group, the first thoughts of parents were about: the child's future (58.3%), what's next (33.3%), the need for information (33.3%), panic (12.5%), not able to think (4.1%), and sadness (25%). Parents first thoughts also included the question why me? why my child? (37.5%)

In the Romanian group, parents' first thoughts were about the child's future (23.3%), what's next (23.3%), the need for information (46.6%), panic (26.6%), not able to think (10%) and sadness (23.3%). Parents first thoughts also included the question why me?, why my child? (43.3%).

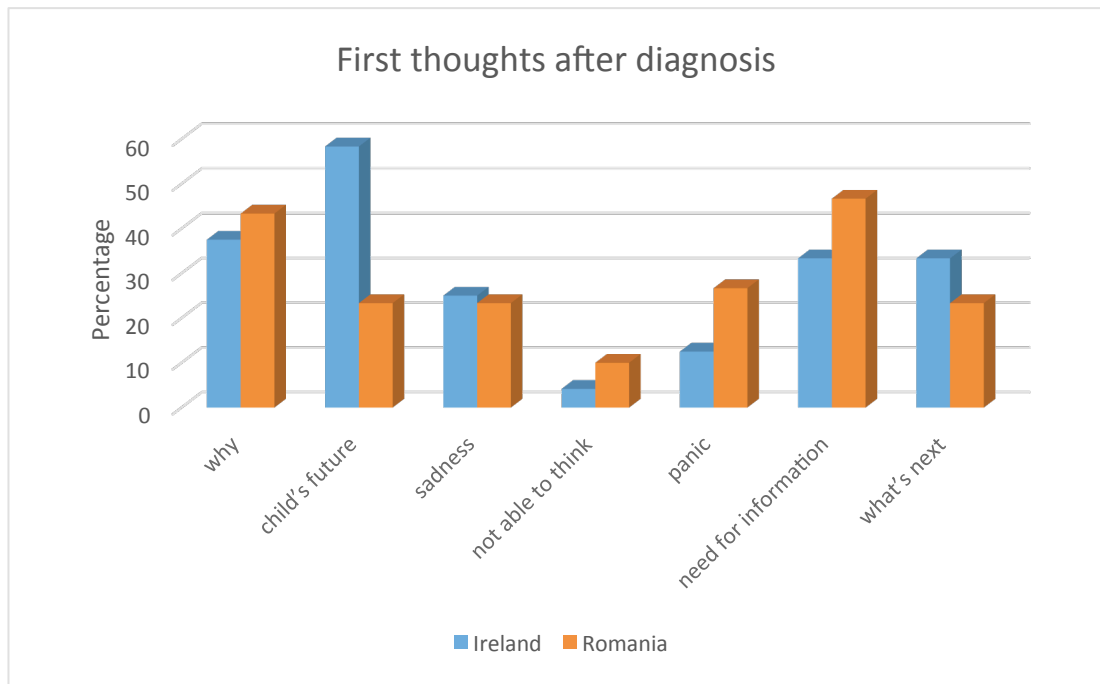


Figure 9-32. First thoughts after diagnosis (Irish vs Romanian).

Answers to the next question in the interview which included family's experience in accessing services were grouped in two categories, positive and negative (Figure 9-33).

In the Irish group, 100% of families had a negative experience in accessing services for their child. Their answers included: "Services are horrible here. No services. I do not want to think about it. It's a joke what is going on."

In contrast, in the Romanian group, 90% reported having a positive experience in accessing services for their child and only 6.6% had a negative experience.

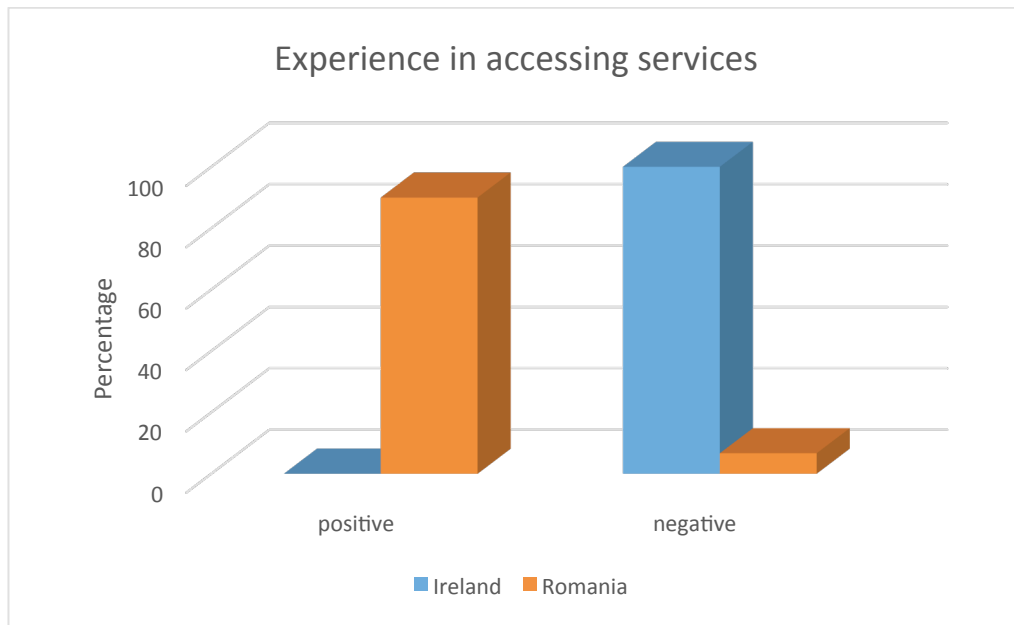


Figure 9-33. Experience in accessing services (Irish vs Romanian).

Answers to the next question in the interview which included the family's experience in accessing educational services were grouped in two categories, positive and negative (Figure 9-34).

In the Irish group, 91.6% reported having a negative experience in accessing educational services and just 8.3% reported a positive experience.

In the Romanian group, 86.6% had a positive experience in accessing educational services in Romania and 10% had a negative experience in accessing educational services.

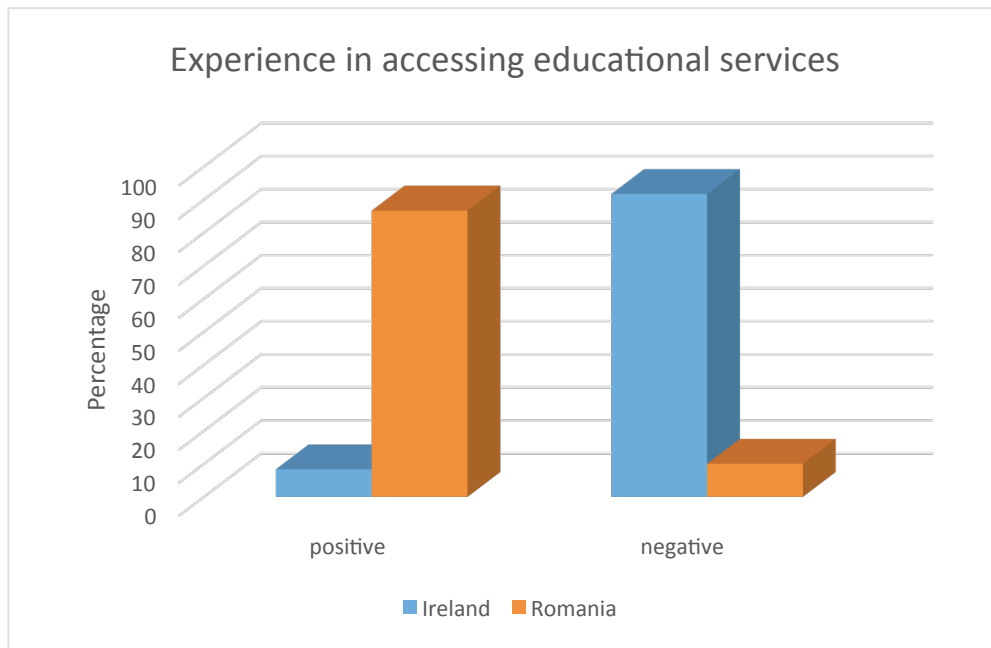


Figure 9-34. Experience in accessing educational services (Irish vs Romanian).

Answers to the next question in the interview which included grandparents' experience in dealing with the ASD diagnosis of their grandchild included: stress, denial, sadness, shock, no understanding, no involvement/they don't know, focus on helping (Figure 9-35)

In the Irish group, parents mentioned that grandparents experienced high levels of sadness (45.8%), stress (33.3%), denial (20.8%), shock (37.5%), no involvement/they didn't know (16.6%). Nobody mentioned a focus on helping.

In the Romanian group, parents mentioned that grandparents experienced high levels of stress and denial (23.3%), sadness and shock (16.6%), no involvement/they didn't know (16.6%). A high number of parents declared that grandparents' experience included mainly a focus on helping (53.3%)

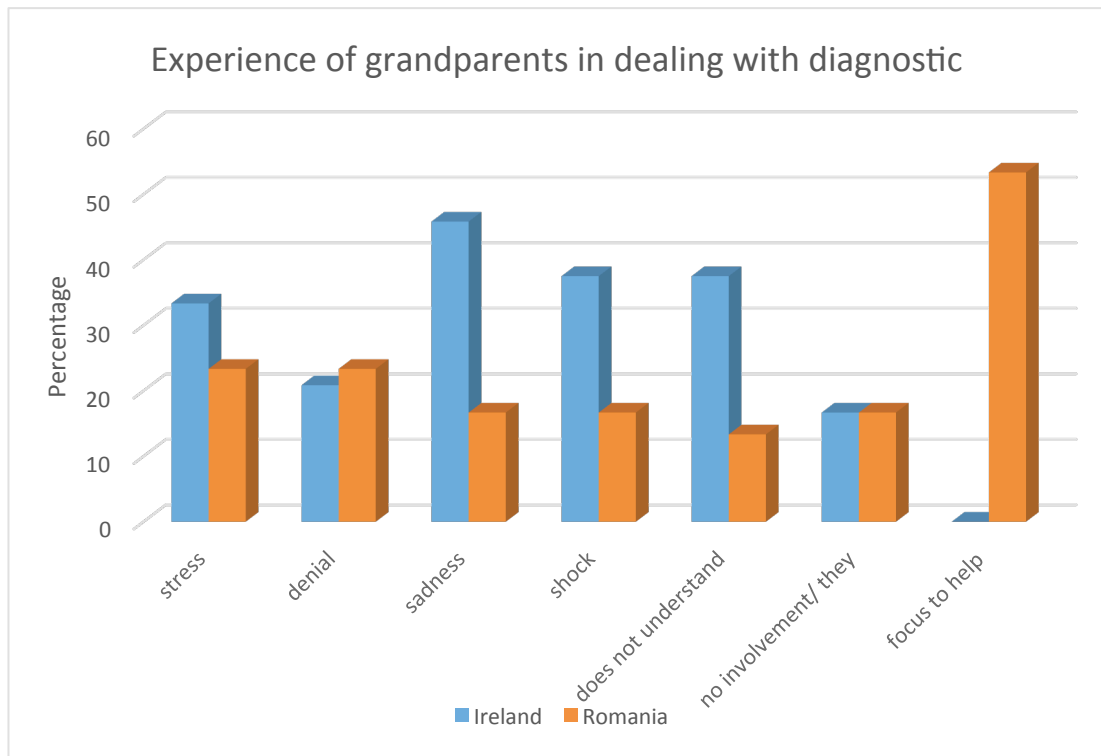


Figure 9-35. Experience of grandparents in dealing with diagnosis (Irish vs Romanian).

Answers to the next question in the interview, which included the effect of diagnosis on parents included: more stress, conflict, separation and more stronger/closer (Figure 9-36).

In the Irish group, parents experience more stress (62.5%) as a result of ASD diagnosis of their child and its impact on them as parents. Conflict was experienced by 33.3%, separation was reported by 29.1% and 33.3% declared that the diagnosis made them stronger/closer.

In the Romanian group, parents experience more stress (60%) as a result of ASD diagnosis of their child and its impact on them as parents. Conflict was experienced by 33.3% and 46.6% declared that the diagnosis made them stronger/closer. Nobody reported separation.

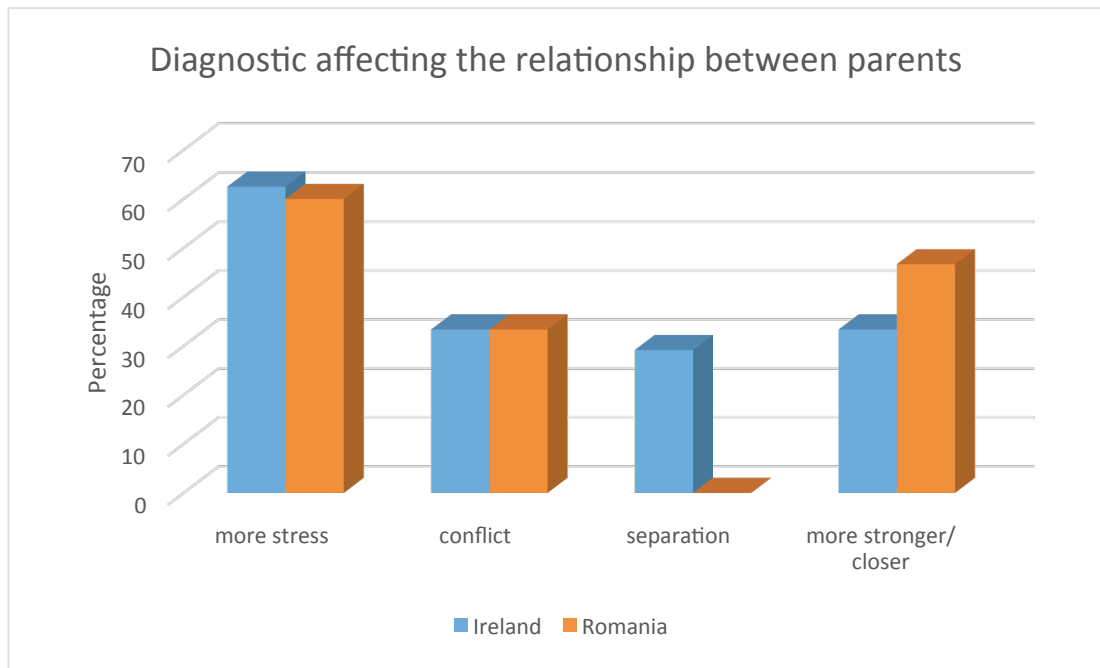


Figure 9-36. How diagnosis was affecting the relationship between parents (Irish vs Romanian).

Answers to the next question in the interview included the effect of diagnosis on siblings were: conflict/stress, confusion, no effect, closer/more involved, no siblings (Figure 9-37).

In the Irish group, parents reported that the effect of diagnosis of ASD on siblings included: conflict/stress (50%), confusion (33.3%), no effect (8.3%), closer/more involved (20.8%), and no siblings (20.8%).

In the Romanian group, parents reported that the effect of diagnosis of ASD on siblings included: conflict/stress (6.6%), confusion (6.6%), no effect (13.3%), closer/more involved (10%), and no siblings (70%).



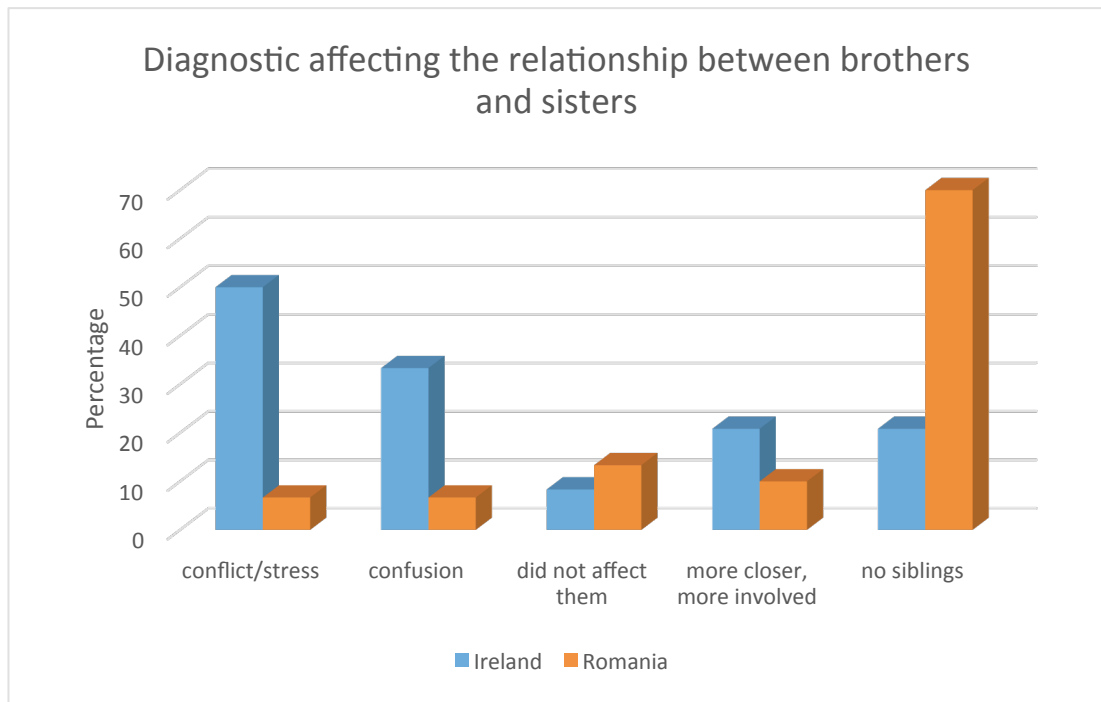


Figure 9-37. How diagnosis was affecting the relationship between siblings (Irish vs Romanian).

Answers to the next question in the interview which included how the diagnosis affected the relationship between family and grandparents included: focus on providing support, more closeness, no effect, same relationship (Figure 9-38).

In the Irish group, parents reported that the relationship between them and the child's grandparents as a result of their child's diagnosis of ASD included: focus on providing support (54.1%), more closeness (25%), no effect (20.8%), and the same relationship (12.5%).

In the Romanian group, parents reported that the relationship between them and the grandparents as a result of their child's diagnosis of ASD included: focus on providing support (53.3%), more closeness (0%), no effect (16.6%), and the same relationship (43.3%).

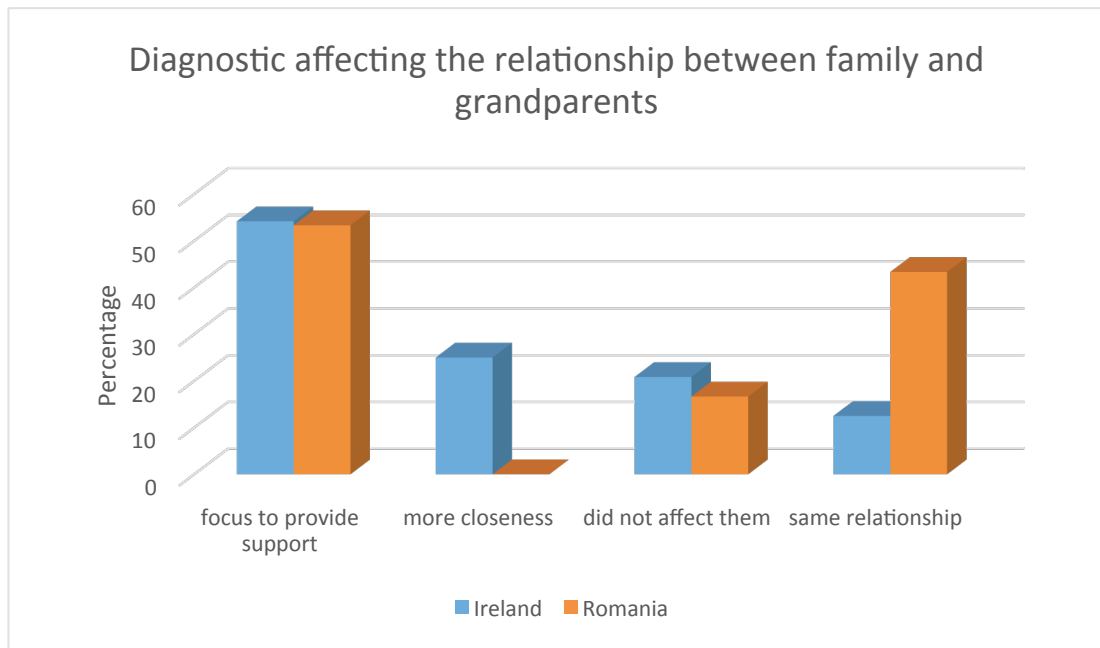


Figure 9-38. How diagnosis affected the relationship between the family and grandparents.

The last question in the interview included parents' perception about improvements in the process of ASD diagnosis in their own country. The answers included (Table 9-46): quicker, reduce bureaucracy, post-diagnostic support, more diagnostic centre and early intervention services, more information about ASD, no need to improve and training for professionals.

Figure 9-39 shows differences between the two countries. In the Irish group, parents reported that they would like the process of diagnosis to be quicker (83.3%), reduce the level of bureaucracy (16.6%), increased post-diagnostic support (12.5%), have more diagnostic centres and early intervention services (20.8%), have more information about ASD (20.8%), there was no need to improve (0%) and there was need for training of professionals (12.5%).

In the Romanian group, parents reported that they would like the process of diagnosis to be quicker (3.3%), reduce bureaucracy (0%), post-diagnostic support (0%), more diagnostic centres and early intervention services (20.0%), more information about ASD (3.3%), no need to improve (63.3%) and training for professionals (26.6%).

Table 9-46. Improvements of diagnostic process: question and answers.

Question	Response	Ireland (%)	Romania (%)
Improvement of diagnostic process	quicker	83.3	3.3
	reduce bureaucracy	16.6	0
	post diagnostic support	12.5	0
	more diagnostic and early intervention services	20.8	20
	more information about ASD	20.8	3.3
	no need to improve	0	63.3
	training for professionals	12.5	26.6

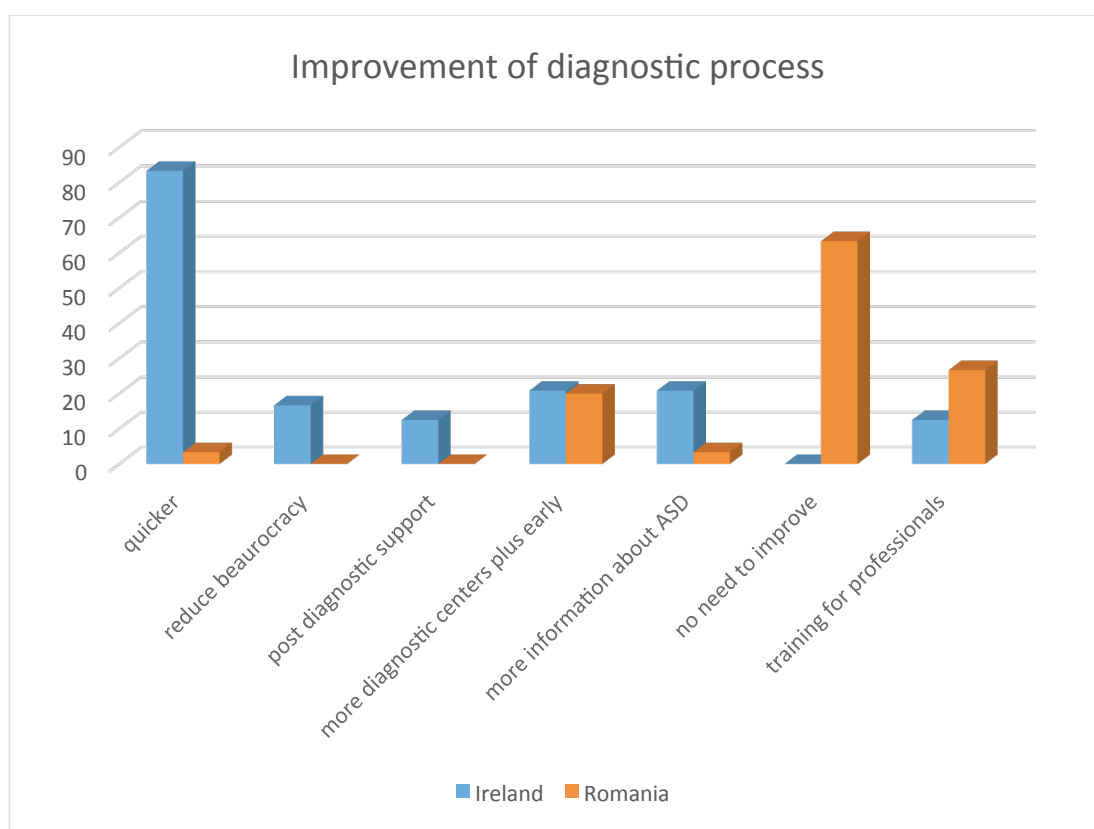


Figure 9-39. Improvement of diagnostic process.

### 9.8. Hypothesis 6 – Age of diagnosis and duration of diagnosis

The age of children when diagnosed with ASD and the duration of the diagnosis process in Ireland were different than the age of children when diagnosed with ASD and duration of diagnosis in Romania. Thus the null hypothesis that there *is no difference between Romanian and Irish children when diagnosed regarding their age and duration of diagnosis was not upheld.*

Comparing the average age of diagnosis in Irish and Romanian groups showed the mean age for the Irish group was 42.75 months, while the mean age for the Romanian group was 36.03, a difference of 6.717. On average, the Romanian children were diagnosed six months earlier than the Irish children (Table 9-47).

Table 9-47. Age when diagnosed: comparison of means.

	Country	Mean	Std. Deviation	Mean Difference	% Mean Difference	Significant?
Age when diagnosed (months)	IE	42.75	9.018	6.717	15.7	Yes
	RO	36.03	10.420			

According to the t-test results shown in Table 9-48 this difference was statistically significant ( $p < 0.05$ ).

Table 9-48. Age when diagnosed: t-test results for equality of means.

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Age when diagnosed (months)	2.496	52	.016	6.717	2.691

This difference was also visible in the distribution of diagnosis age shown in Figure 9-40.

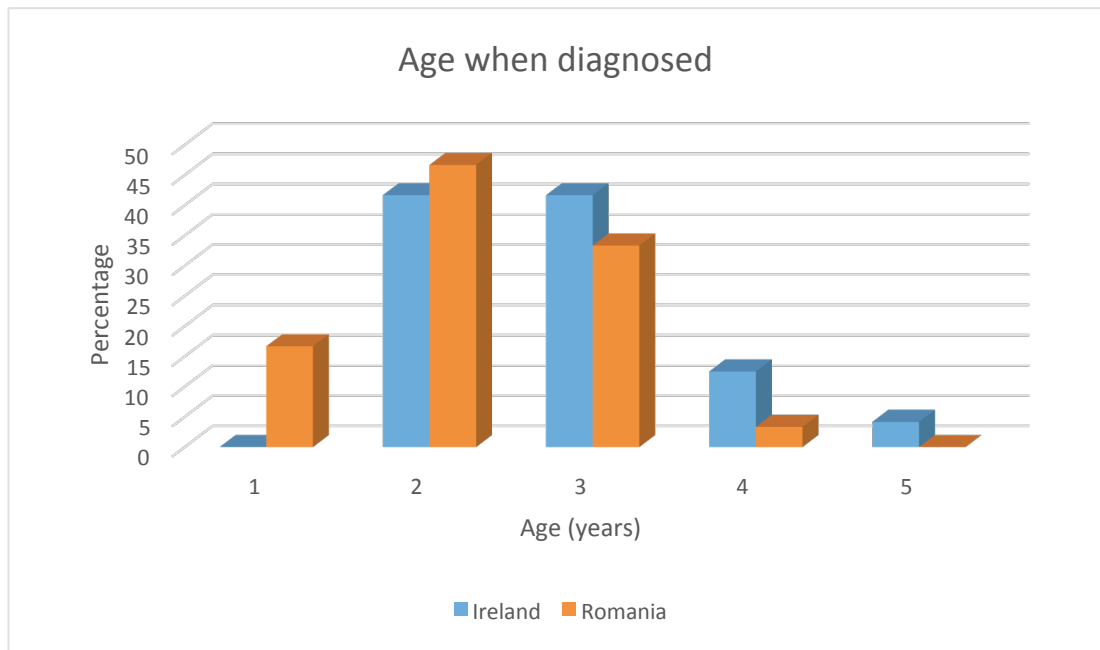


Figure 9-40. Distribution of age when diagnosed (Irish vs Romanian).

As previously mentioned, the average duration of diagnostic process (parents' first appointment for assessment until completed) in the Romanian group was 4.63 months and the average duration of diagnostic process in Irish group was 14.92 months. In Romanian group, the process of diagnosis was 10 months quicker than the Irish group.

According to the t-test (Table 9-14), the difference between the means of the two groups was statistically significant ( $p < 0.05$ ) in terms of duration of diagnostic process.

Figure 9-10 shows the length of time it took for the diagnosis in Ireland and Romania using intervals from <6 months to 25–30 months. In Romania, 70–80% of children were diagnosed before 6 months, 40–50% were diagnosed between 7–12 months, 10–20% were diagnosed between 13–18 months, and 20–30% were diagnosed between 19–24 months. In Ireland, 0–10% were diagnosed before 6 months, 40–50% were diagnosed between 7–12 months, 10–20% were diagnosed between 13–18 months, 20–30% were diagnosed between 19–24 months and 0–10% were diagnosed between 25–30 months.

## 10. Discussion

The purpose of the study was to examine the impact of diagnostic upon families of having a child with ASD in two European cultures, Ireland and Romania. Similarities and differences between the two countries were considered to provide valuable information regarding family's experience during the diagnostic process of their child/ren.

As described in Chapter 1.4., ASD seems to vary in different cultures. Present study confirms that there are differences and similarities in how parents face the diagnosis of ASD of their child in two different cultures (Ireland and Romania).

The original facet of this study is its comparative value in understanding parents' experience of their child's diagnostic of ASD in different cultural contexts (Ireland and Romania)

As the literature suggest, parents' decision and understanding of autism is influenced by culture (Mandell and Novak, 2005). Present finding might be linked with parents' cultural influences regarding the diagnostic process of their child.

Cultural differences can be interpreted as having an influence on parents' perception and experience during the diagnostic process of their child. Specific cultural influences may have an effect on parents' perception/experience of their child's diagnosis. For example, one interpretation regarding parents' worries when received the diagnosis, parents' awareness/knowledge about ASD, and parents' level of involvement, can be linked with the legislative and socioeconomic situation in each country. In Romania, the low level of family income and the corrupted medical, educational and governmental systems, the lack of implementation of legislation, encouraged parents to become more involved in their child's development. In contrast, clear implementation of legislation in Ireland regarding children with disabilities, financial support for children with disabilities and their parents can be linked with a low level of parental involvement. Another interpretation of family experience can be associated with the political legacy in each country. During the communism era, Romanian people were deprived of information, services, food and

free speech. Ireland did not experience such disadvantages. Romanian families needed to do everything for their child. They did not receive support from other people and institutions and this led them to become more involved in their child's development.

The role of mother and the role of father in raising a child with autism (Hypothesis 4) is mostly associated with cultural influences. Findings suggest that parents from both groups identified almost the same roles (except for two mother's roles: financial aspects and controlling) but the degree of embracing those roles is different for each group.

As hypothesized, families of a child with ASD in Ireland displayed different experience during the diagnostic process of their child compared to the Romanian families. Differences were also found between the two groups with regard to the role of the mother and the father in raising a child with ASD; parents' worries when received the diagnosis; parents' awareness/knowledge about ASD; and parents' level of involvement. The duration of the diagnostic process was significantly different between the two countries. Finally, aspects of family functioning were tested using FACES IV (Olson et al., 2010) and found similarities and differences between the two groups in terms of mean scores for family cohesion, flexibility, communication and satisfaction. All six hypotheses were supported and only Hypothesis 1 was partially supported.

The Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was released in May 2013. This edition includes only the term autism spectrum disorder (299.00) under the Neurodevelopmental disorders' section. PDD was replaced by autism spectrum disorder (ASD), the term Asperger syndrome is no longer used in DSM5 and instead ASD is defined along three levels of severity. However, since the fieldwork reported in this thesis was conducted prior to the publication of DSM5, for the context of this thesis, the DSM-IV definitions are used throughout. A wide body of literature has accumulated about diagnosis and science-based intervention for children with autism and their families.

*Inclusion criteria* for families was:

- that they have at least one child between 2 and 7 years diagnosed with ASD according to ICD 10 F84.0 and DCM IV 299.00 criteria;
- that the diagnosis was no more than 1 year old.

The uniqueness of this comparative research is that no previous studies have focused on the impact of ASD diagnostic on family systems across two cultures in Europe. Similarities and differences found offer valuable information in the field of autism and validate the value of comparative studies.

It must be specified that an unpredicted aspect interfered with data collection and this may bias the actual representation of family's experience during the diagnostic process of their child in Ireland. A significant number of Irish families refused to participate in this research, or accepted initially and then rejected afterwards. Only 24 families out of 77 families contacted choose to participate in this study. Fifty-three families declined the invitation to participate. In contrast, all 30 Romanian families who were contacted to participate in this research accepted the invitation; there were no Romanian refusals to participate.

It is difficult to delineate exactly why this may have been the case. These aspects could be correlated to differences found between the experience of the Irish group and the Romanian group in terms of the duration of diagnosis process and access to services and subsequently their level of involvement, worries and ASD awareness/information. In Ireland, the enormous amount of time it took to reach a diagnosis and the lack of services for children with ASD may possibly have influenced parents' decision not to participate when they realized the purpose of this study. In the Irish group, the parents were more focused on child's future and services available (external factors), while in the Romanian group, parents were more focus on what they could do for their child (internal factors).

Another interpretation of the refusal to participate could be that parents always have a choice about how they get their child assessed and what interventions they use. The private option is available to everybody who can afford it. As employee in the public sector, parents may 'omit' to tell us that they attend private services in Ireland or outside the country. However, a few parents informally told us that they attend



private services in Ireland and outside the country. It is difficult to understand exactly the reason why the Romanian family (who returned to Romania to access services for their child) in particular decided to opt for a corrupted system (Romania) instead of a waiting list (Ireland). Could be because of cultural influences, or a pragmatic decision and because of the offer of support from the extended family?

Another interpretation of the refusal of Irish parents to participate in the study could be related to what Amanda Ferguson reported in *The Belfast Telegraph*. She reported a GP as saying that:

the abuse of Northern Ireland's healthcare system by patients from the Republic has the potential to damage services here ... The number of medical cards registered in Northern Ireland is up to 80,000 higher than the number of people who live here – currently around 1.8m.

Possibly, parents refused to participate because they are already attending services for their child, but in a different healthcare system. As the researcher lives in Dublin but attends Queens University Belfast, Northern Ireland may possibly have influenced parents' decision not to participate.

In terms of parental interest, the Romanian group (100%) asked question about ASD and the present research, and other therapies, while in the Irish group, parents did not show this level of interest – only 8.3% asked questions about ASD. The parents' level of information about therapies for children with ASD was significantly different, especially with regard to knowledge about type of therapies and services available for children with ASD. In the Romanian group, families were more focused on continuing therapies at home and engaging in therapeutic activities with their child, while in the Irish group, the focus was on providing care and supervision.

As specified in Chapter 5, an unexpected aspect occurred during the data collection in the Romanian group. A family who lived in Dublin for several years returned to Romania to access services for their child. Because of the inconsistency in service delivery and extremely long waiting list, parents of children with ASD in Ireland were often concerned about the ability of their child to access services. Based on this

family's experience and findings of this research, services for children with ASD in Ireland seem to be uncoordinated and not very well developed.

The experience of this family underlines the findings of this study in terms of Irish and Romanian family's levels of satisfaction about access to services. In the Irish group, 100% of families had a negative experience in accessing services for their child. In the Romanian group, 90% had a positive experience in accessing services and only 6.6% had a negative experience. In the Irish group, 91.6% had a negative experience in accessing educational services and only 8.3% had a positive experience. In the Romanian group, 86.6% had a positive experience in accessing educational services in Romania and 10% had a negative experience in accessing educational services.

The average duration of the diagnostic process in the Romanian group was 4.63 months and the average duration of diagnostic process in Irish group was 14.92 months. In the Romanian group, the process of diagnosis was 10 months quicker than in the Irish group. These findings could lead to parents' dissatisfaction about access to services in Ireland, and compares poorly with the situation internationally, for example in the United States, where evidence-based interventions are more widely supported.

Present findings should be considered by policymakers with regard to improving parent's accessibility to ASD services for their children (diagnostic and post-diagnostic) in both countries. There is a crucial need to develop specialised services for children with ASD.

Based on our findings, in the Romanian group, parents' level of information and involvement was higher than in the Irish group. This could demonstrate that the level and complexity of services that parents have access to in the Romanian group is higher than in the Irish group.

## 1. Family functioning in families of children with ASD

This study explored family functioning during the diagnostic process of ASD. The results led to a better understanding of families from different cultures and therefore enable professionals to respond early in order to support families holistically and effectively, in order to promote child-family-centred assessment and intervention (Dover and LeCouteur, 2007).

Many previous studies have investigated aspects of family functioning in children with ASD (Ogston et al., 2011; Osborne et al., 2008; Hastings, Honey and McConachie, 2005; Bromley et al., 2004; Wing, 1997; Gray, 1994; Noh, Dumas, Wolf and Fisman, 1989). Family adaptability and cohesion evaluation scales (FACES) is a useful instrument that has been used in various studies to emphasize aspects of family functioning in children with ASD (flexibility, cohesion, communication, satisfaction) (Shur-Fen Gau et al., 2012; Baker et al., 2011; Di Nuovo and Azzara, 2011; Higgins et al., 2005).

For example, a recent study used FACES IV to analyse the “relations between the perceptions of the parental couple about the styles of functioning of the family, and the competencies of their autistic children” (Di Nuovo and Azzara, 2011, p. 25). The findings showed that cohesion, communication and satisfaction are higher when intellectual disability is not associated with autism. Higher cognitive scores indicated flexibility, cohesion and communication within the family system. Language and affective expression difficulties showed unbalanced dimensions of family functioning.

For the present study, FACES IV was selected to explore aspects of family functioning (cohesion, flexibility, satisfaction and communication) during the diagnostic process of children with ASD in Ireland and Romania.

The findings from FACES IV show that Irish and Romanian families demonstrated different levels of family cohesion, flexibility, communication and satisfaction, during the diagnostic process of their child as discussed below.

## Cohesion and flexibility levels

*Balanced and unbalanced levels* for the Irish group showed 80–90 percentile *very connected* levels (balanced cohesion) and *flexible* >60 and *very flexible* levels 30–40 percentile (balanced flexibility). The unbalanced levels showed *very low levels* for disengaged, enmeshed and chaotic and *low and moderate* for the rigid level.

*Balanced and unbalanced levels* for the Romanian group showed >60 percentile *connected levels* (balanced cohesion) and *flexible* >60 level percentile (balanced flexibility). The unbalanced levels showed *very low levels* for disengaged and chaotic, *low levels* for rigid and enmeshed.

## Communication and satisfaction levels

*Family communication* scores in the Irish group showed that the average family communication was 75.88 which shows a *high level of communication*.

*Family satisfaction* scores in the Irish group showed that the average family satisfaction was 54.58 which shows a *moderate level of satisfaction*.

*Family communication* scores in the Romanian group showed that the average family communication was 66.17 which shows a *high level of communication*.

*Family satisfaction* scores in the Romanian group showed that the average family satisfaction score was 35.43 which shows a *low level of satisfaction*.

In conclusion, the scores for balanced cohesion, balanced flexibility and unbalanced scores did not show significant differences between the two groups. Only, the family satisfaction score was lower in the Romanian group when compared with the Irish group.

## The average cohesion and flexibility scores

*The average cohesion score* in the Romanian group was 65.07 while in the Irish group it was 76.08, with a difference of 11.017 (or 14.4%) between them. According to the t-test results shown in Table 9-29, this difference was statistically significant ( $p < 0.05$ ).

*The average flexibility score* in the Romanian group was 54.8, while in Irish group was 62.54, with a difference of 7.742 (or 12.3%) between them. According to the t-test results, this difference was statistically significant ( $p < 0.05$ ).

The average cohesion and flexibility ratio scores

*The average cohesion ratio score* in the Romanian group was 2.6 while in the Irish group the average was 4.16, with a difference of 1.55 (or 37.2%) between them. According to the t-test results shown in Table 9-31, this difference was statistically significant ( $p < 0.05$ ).

*The average flexibility ratio score* in the Romanian group was 1.75 while in the Irish group it was 2.29, with a difference of 0.53 (or 23.1%) between them. According to the t-test results shown in Table 9-31, this difference was statistically significant ( $p < 0.05$ ).

Finally, *the total ratio score* in the Romanian group was 2.18 while in the Irish group it was 3.22, with a difference of 1.04 (or 32.3%) between them. According to the t-test results shown in Table 9-31, this difference was statistically significant ( $p < 0.05$ ).

Overall, according to the ratio scores, there was an important difference between the Irish and Romanian groups. The families in the Irish group had on average a more balanced family system in terms of both cohesion and flexibility than the families in the Romanian group.

The average communication and satisfaction scores

*The average communication score* in the Romanian group was 66.17, while in Irish group it was 75.88, with a difference of 9.708 (12.8%) between them. However, according the t-test results shown in Table 9-33, this difference was not statistically significant ( $p > 0.05$ ).

*The average satisfaction score* in the Romanian group was 35.43, while in Irish group it was 54.58, with a difference of 19.15 (35%) between them. As per t-test results shown in Table 9-33, this difference was statistically significant ( $p < 0.05$ ).

According to the results on family satisfaction scores, there was an important difference between the Irish and Romanian groups. The families in the Irish group were on average more satisfied with their family life than the families in the Romanian group.

## 2. Family worries when they received the diagnosis of ASD

Throughout all diagnosis stages, such as, pre-diagnosis, diagnosis, post-diagnosis, and the final stage of acceptance and adaptation (Mansell and Morris, 2004), parents expressed their worries regarding their child with ASD. This is particularly apparent during the diagnosis stage, when they have been informed about their child's diagnosis.

The present findings confirmed that confronting parents with this new information involves worries and questions. The need for information is more frequently reported by families than other needs (Bailey and Powell, 2005). In relation to family worries when receiving the diagnosis of ASD, present findings suggest that parents were focused on themselves as parents – internal factors (what can I do for my child), external factors (future, services), and child focus (able to live independently, able to talk, learn and improve, relationship with siblings, child will be ok) (Figure 9-17).

In the Irish group, 40% of the interviewed families were concerned about the future of their child (external factor), 20–30% were concerned about the availability of the supporting services (external factor), 30–40% were worried about the fact that she/he may not be able to live independently and that she/he may not be able to talk, learn or improve (child focus). Only a few parents (0–10%) were concerned about their relationship with their sibling (child focus), if he/she will be ok (child focus) and what they can do for their child 0–10% (internal factor)

The families in the Romanian group shared some of the concerns of the Irish families, such as the future of their child (30-40%) and their future ability to talk, learn or improve (40–50%), but they were less concerned with the availability of the supporting services, if the child will be ok, their relationship with their siblings and the fact that she/he may not be able to live independently (0–10%). Also, more than a half of the interviewed Romanian families (50–60%) were worried about what they could personally do to improve their child's condition (internal factors).

The difference in responses between the two groups were statistical significant in 'live independently' and 'what can I do for my child'. These findings confirm the issues raised by other researchers, especially in the Irish context (Keenan et al., 2007).

In conclusion, the main family worries about their child when receiving the diagnosis in Ireland were different than the family worries about their child when receiving a diagnosis in Romania with a focus on internal or external factors. Since this is the first study of families in Romania, there is no comparative data in the literature.

### 3. Level of involvement

The family's opportunity to discuss their child's diagnosis with different people was explored. The Romanian group discussed their child's diagnosis with everybody (66.65), while in the Irish group only 45.8% had discussed their child's diagnosis widely. Both groups discussed their child's diagnosis with family members and with the extended family. The findings of this study show that, on average, the Romanian families had a higher level of involvement (70% higher) when compared to Irish families.

The family's opportunity to discuss their child's diagnosis with other parents who have children with ASD was also assessed. Both groups discussed their child's diagnosis with other families who have children with ASD (70% Romanian group and 62.5% Irish group). The positive impact of parent support groups in families of

children with ASD has been highlighted in the literature (Mandell and Salzer, 2007; Luther et al., 2005;).

The need for information is frequently reported by families rather than other needs (Bailey and Powell, 2005). During the diagnosis process, parents need information. The need for information is probably the first need when parents are being informed about their child's diagnosis. Information can be requested by parents or offered by professionals involved in diagnosis.

Parents' knowledge about ASD can be linked with parents' level of involvement in their child's intervention. In Romania, parents' knowledge about ASD and their interest in asking questions at the end of the interview was high. They were able to continue therapies at home and be involved in play/free activities. Family's knowledge in relation to type of services/therapies that they were aware of (Figure 9-21) were: physiotherapy, occupational therapy, speech and language therapy, early intervention, therapeutic listening, PECS, ABA, music therapy, horse-riding and dogs, nothing, sensory integration, art therapy, TEACCH and medication. The Romanian group described a lot of services and therapies for children with ASD (between 66.6% and 86.6%). They mentioned that their children attend almost all of these therapies. Only 10% stated that they do not have information about therapies. In the Irish group, a high percentage mentioned speech and language therapy (62.5%). They mentioned that their child attended this form of therapy or they were on the waiting list for it. Nobody mentioned music therapy, TEACCH or art therapy. Only 16.6% stated that they do not have information about therapies.

Stress was described in many studies as affecting parents of children with ASD (e.g. Stuart and McGrew, 2009; Duarte et al., 2005; Honey et al., 2005; Hutton and Caron, 2005; Hastings, 2003; Sivberg, 2002; Weiss, 2002; Dunn et al., 2001; Konstantareas, 1992) and emphasized by parents in this study. Stress factors could contribute to parent's ability to support their children. Osborne et al. (2008) highlighted that greater levels of family stress have reduce the efficacy of home-based, early teaching interventions. Parents' involvement in home-based interventions for children with ASD was widely studied (e.g. (Solish and Perry, 2009; Magiati et al., 2007; Sallows and Graupner, 2005). Involving parents of children with ASD as therapists for their



children has been emphasized by Matson et al. (2009) in a study that involves need for training for parents. In the Irish group, the level of stress experienced daily by parents conducted to a low level of involvement in continuing therapies with their child at home. In the Romanian group, low levels of daily stress resulted in more involvement in children's therapies at home by parents.

In the present study, parents' regular day with their child consisted of: constant care and supervision, lot of stress, continuation of therapies at home, and free activities. A high percent of the Romanian group described that they did free activities (90%) and continued the therapies at home with their child (73.3%). Stress (20%) and constant care and supervision (10%) was mentioned by a small percentage of parents. In the Irish group, the majority described a regular day with a lot of stress (41.6%), free activities (50%) and constant care and supervision (66.6%). Only 25% of families continued the therapies at home with their child.

A large community of Romanians came to work and live in Ireland. Today, the Romanian community is the sixth most common non-national community in Ireland. According to the Central Statistics Office (2012), the period between 2006 and 2011 showed the fastest growth in the number of non-Irish in the population in Ireland. The Irish population was 88% and 12% other non-Irish population: 1. Poland (2.7%), UK (2.5%), Lithuania (0.8%), Latvia (0.5%), Nigeria (0.4%), Romania (0.4%) and other (4.7%). Parents' knowledge about children with autism from their own country and from the other country was different. In the Irish group, 46% of families had information about children with ASD in Ireland, while 54% said that did not have information about children with ASD in Ireland. As many as 67% of Irish families mentioned that they do not have any information about children with ASD from Romania. A third (33%) of Irish families declared that they had some information about children with ASD from Romania. Their answers were:

"I know about Romanian gypsies ... they stay on O'Connell Street. Probably services are worse than here. Romania is a poor country. I think Romania has no services for children with autism. I now about Ceausescu and communism ... I saw a TV programme about orphanages from Romania. Romania is an isolated country."

On the other hand, 83% of Romanian families stated that they had information about children with autism in their own country. Also, 60% of Romanian families knew something about children with ASD from Ireland and they mentioned that they thought there were “better services in Ireland”.

Most Romanian parents who participated in this study believed that services for children with ASD are better in Ireland than in Romania. The results of this study suggest while this is probably true in the past, this perception is inaccurate today. The situation in Romania has changed dramatically over time, and services for children with ASD and their parents in Ireland today significantly lag behind those in Romania.

The last question in the interview underlined parents’ interest in research and ASD. The participant information sheet (Appendix 1) included encouragement to ask questions. The level of involvement included parents’ answers to the last question of the semi-structured interview: *Do you have any questions?* All participants in the Romanian group (100%) asked questions about this study, ASD, ABA, research in ASD and other therapies. Only 8.3% in the Irish group asked questions about ASD and research in ASD. The results indicate parents’ level of involvement in their child’s development and showed the low level of interest in this study and research in ASD in general.

#### 4. The role of the mother and the role of the father

As described in Chapter 4 and Chapter 5, families from Ireland and Romania present a unique set of characteristics in relation to their history, access to services, legislation framework, assessment and diagnostics. A wide body of literature on parents of children with ASD suggest positive and negative aspects that are largely reflected in the findings reported in this research (e.g. stress, parenting, coping, parental well-being, attachment, family functioning, the family life cycle, and the diagnosis process). As expected, the life of parents with children on the autistic spectrum involved many roles, some of them similar to parents of typically

developing children and some of them quite challenging. Despite research findings in the autism field and more awareness about autism and family systems, parents are the only ones who know what it really means to live with a child with autism.

Participants who took part in this study were mainly mothers, which reflects participation more generally in the literature; generally fathers are underrepresented in research and intervention of autism spectrum disorders and there is a need for more father involvement (Braunstein et al., 2013; Flippin and Crais, 2011). Although fathers were welcome to take part, their lack of participation was an obvious limitation of the present study. In further studies, researchers should considered a *sine qua non* condition of fathers' participation in order to have a *child-family centred* assessment and intervention (Dover and LeCouteur, 2007).

Few studies investigated the role of mothers and fathers in raising a child with ASD, for example, Flippin and Crais (2011) compared the roles of fathers and mothers and reviewed 404 papers.

Of course, both parents' role is important in the assessment and intervention of children with an autistic spectrum disorder (ASD), especially in the early intervention services (McConachie and Diggle, 2007). Ultimately, parental involvement in ASD has a crucial role in the child's development, and children with ASD are not exception (e.g. Laugeson et al., 2009; Matson et al., 2009; Munteanu, 2009; Rocha et al., 2007; Symon, 2005)

Not surprisingly, Irish families were found to have a different perspective about the role of the mother/father in raising a child with ASD than Romanian families. With regard to the mothers' roles, the difference in responses between the two groups were statistical significant around the following roles: "the same as father", "emotional support", "to control everything", "financial aspects". With regard to the fathers' roles, the difference in responses between the two groups were statistical significant around one role: "the same as mother". The results show that in both groups, Irish and Romanian, parents shared some roles but also believed that other roles are specific to one gender (mothers or fathers). Pleck and Masciadrelli (2004) suggest

that in American families, the role of the mother is predominantly as a caregiver and the role of father is frequently associated with play.

Literature suggest that father's play is more rough and tumble and father-child play is more active (Labrell, 1996). Literature indicates that both mothers and fathers play equal roles in the development of their children, particularly in their social-communication skills (Pancsofar and Vernon-Feagans, 2006; Shannon, et al., 2002). In the Romanian group, the role of father and the role of mother was perceived as being similar (60–70%), while in the Irish group, the role of mother is predominantly “to do everything” (30–40%) and “to stay at home with children”, “provide emotional support” and “the same as father” (20–30%). In the Irish group, the role of father was “to work” and “similar to mothers” (30–40%)

## 5. Experience of diagnostic process

A positive or negative experience within the diagnostic process of ASD has a significant impact on a parent's reaction to the diagnosis (Watchtel and Carter, 2008; Mansell and Morris, 2004; Nissenbaum et al., 2002; Howlin and Moore, 1997; Leff and Walizer, 1992). According with Mansell and Morris (2004) the process of diagnosis involves at least four stages during which families experience a range of emotions: pre-diagnosis, diagnosis, post-diagnosis, and a final stage of acceptance and adaptation. It was hypothesized that the experience of family regarding their child when received diagnosis in Ireland was different than the experience of family regarding their child when received diagnosis in Romania. Positive and negative scores were calculated. The mean score for the Irish group indicated a completely negative experience overall. The mean score for the Romanian group showed a more neutral experience, rather than a negative one. Overall, the Romanian families had a better diagnostic experience when compared to Irish families.

Changes in family life (e.g. more stress, changes in all aspects of family life, separation, more supportive, quit work, no changes, and focus on child with ASD) were experience by both groups in this research. Similar changes in family life (66.6%) were observed in both groups in relation to more stress experienced since

they received the diagnosis. Significant changes were observed in both groups regarding changes in all aspects of family life (58.3% in the Irish group and 36.6% in the Romanian group), separation (16.6% in the Irish group and 3.3% in the Romanian group), and no changes (12.5% in the Irish group and 6.6% in the Romanian group).

The effect of a diagnosis on parents in the present study included: more stress, conflict, separation and more stronger/closer. In both groups, more stress was the primarily effect of a child's diagnosis on parents. In the Irish group, separation was also an effect of a child's diagnosis, while in the Romanian group nobody experienced separation. A vast body of literature emphasized the impact of stress on parents with children on the autism spectrum disorder which was experienced by both groups in the present study (Benson and Karlof, 2009; Pottie and Ingram, 2008; Duarte et al., 2005; Honey et al., 2005; Weiss, 2002; Dunn et al., 2001; Gray, 1994; Norton and Drew, 1994; Bristol and Schopler, 1983). Little research has been focused on the parents of children with ASD and risk of divorce or separation. A recent study in the United States found that there is "no evidence to suggest that children with ASD are at an increased risk for living in a household not comprised of their two biological or adoptive parents' (Freedman et al., 2012, p. 545)

Parents of autistic children often experience reactions to diagnosis similar to the stages of grief (e.g. shock, anger, grief, guilt, denial, etc.) (Baba et al., 2004; Gray, 1994). Chamak et al. (2011) demonstrated that those parents who received their child's diagnosis when the child was around four years, experienced reactions of disbelief, shock and anger. In relation to family's feelings about child's diagnosis (e.g. shock, denial, anger, blame, sadness, worries about future and services, not able to describe feelings), in the Romanian group, families experienced more denial 73.3% in comparison to the Irish group (29.1%). Shock was experienced by 50% in the Irish group and 36.6% in the Romanian group. Other feelings included anger (25% in the Irish group and 13.3% in the Romanian group), sadness (66.6% in the Irish group and 33.3% in the Romanian group) and blame (16.6% in the Irish group and 10% in the Romanian group). In the Irish group, 25% were not able to describe their feelings and in the Romanian group, 50% were not able to describe their feelings when they received the diagnosis. Parents also included worries about the

future and services when they received the diagnosis (12.5% in the Irish group and 20% in the Romanian group).

According to family's first thoughts when received the diagnosis (e.g. what's next, need for information, panic, not able to think, sadness, child's future and why?), in the Irish group the first thoughts were in relation to child's future 58.3%, why? 37.5%, while in the Romanian group first thoughts included the need for information (46.6%) and why? (43.3%).

Family's positive and negative experience in accessing services (for diagnostic and intervention) and educational services was significantly different between the two groups. In the Irish group, 100% of families had a negative experience in accessing services for their child: "Services are horrible here. No services. I do not want to think about it. It's a joke what is going on." In the Romanian group, 90% had a positive experience in accessing services and only 6.6% had a negative experience. In terms of accessing educational services, the majority (91.6%) of the Irish group had a negative experience and the majority (86.6%) of the Romanian group had a positive experience.

Autism may have impact on other family members, such as siblings and grandparents. The findings of a study on siblings with ASD and ID found that the siblings of children with autism and ID may be at increased risk of emotional problems which can persist over time (Petalas et al., 2009). Other studies found that siblings of children with ASD may not be at risk to develop negative behavioural changes comparing to siblings of children with another disability (Hastings, 2007; Pilowsky et al., 2004). The effect of diagnosis on siblings in this research included: conflict/stress, confusion, no effect, closer/more involved, and no siblings. In the Romanian group, 70% had no siblings and the primary effect on siblings was "no effect". In the Irish group, only 20.8% had no siblings and the primary effect on siblings was conflict/stress (50%) and confusion (33.3%).

Hutton and Caron (2005) suggested that the family as a whole, including parents, siblings, grandparents, are all greatly affected by the diagnosis. In addition, this study

suggested that families who have a child with ASD share the same feelings of frustration, stress and hope for the future. The grandparents' experience in dealing with the ASD diagnosis of their grandchild in the present study included: stress, denial, sadness, shock, no understanding, no involvement/they don't know, focus on helping. In the Irish group, the main experience included: sadness (45.8%), while in the Romanian group the grandparents' focus was to help (53.3%). The effect on the relationship between parents and grandparents as a result of a child's diagnosis included: focus on providing support, more closeness, no effect, same relationship. The main effect in both groups was that the grandparents were focus on helping and providing support to the family.

Other studies have demonstrated that a considerable number of families of children with autism display factors of resilience (positive meaning of disability, mobilization of resources, united and closer, appreciation of life, spiritual strength) and become stronger as a consequence of autism in the family (Bayat, 2007).

In the present study, Romanian families showed that a child's diagnosis made them more supportive (10%) as a result of autism in family life, while in the Irish group 12.5% demonstrated that a child's diagnosis made them more supportive.

As the literature indicated (Bayat, 2007), the present study also demonstrated that the effect of autism on family resulted in a stronger relationship between parents (33.3% in the Irish group and 46.6% in the Romanian group). The Irish group showed that 20.8% of siblings became closer and more involved, and in the Romanian group 10% became closer and involved. In the Romanian group, 53.3% of grandparents were focused on helping following the ASD diagnosis of their grandchild and in the Irish group, 54.1% of grandparents wanted to provide support. (Table 9-45)

Parents' perception about improvements in the process of ASD diagnosis included: to be quicker, to reduce bureaucracy, more post-diagnostic support, more diagnostic and early intervention services, more information about ASD, no need to improve and training for professionals. In the Irish group, 83.3% wanted the diagnostic process to be quicker. In the Romanian group, the majority mentioned that there was no need for improvement.

## 6. Age of diagnostic/duration of diagnostic process

The diagnostic process, from referral to final determination and the age when children are diagnosed with ASD involves parents' initial concern about their child's development, professionals who are involved in monitoring toddlers such as baby nurses, GP etc, professionals who work in diagnostic and legislation framework, and so on). Findings reported here confirm that in Ireland, the diagnostic process still takes on average 16 months to complete, despite the fact that Keenan et al. (2007) called for the diagnostic process to be shortened. In Romania, results reported here show timescales for diagnosis that were much shorter, although there is no literature to identify the duration of diagnosis in Romania.

A recent study conducted by Moh and Magiati (2012) in Singapore, found that the average duration of the diagnostic period, from first recognizing concerns to obtaining a diagnosis, was 12–13 months and the average age of the children at diagnosis was 3.4 years old. The time interval between first becoming concerned and first consultation with professionals was 6 months. In a Canadian study, Siklos and Kerns (2007) found that parents of children with autism experience difficulties obtaining a diagnosis for their child. Children were diagnosed at approximately 5 years of age. On average, boys were diagnosed at 4.5 years of age, while girls were diagnosed at 6 years of age. In a French study, Chamak et al., (2011) found that the mean age of diagnosis was  $10 \pm 8$  years from 1960 to 1990,  $5 \pm 3$  years from 1990 to 2005 and  $3 \pm 1$  from 2003 to 2005.

In the present study, the average duration of diagnosis in the Romanian group was 4.63 months and the average duration of diagnostic in Ireland was 14.92 months. In the Romanian group the process of diagnosis was 10 months quicker than the Irish group.

Comparing the average age of diagnosis in the Irish and Romanian groups showed the mean age for the Irish group was 42.75 months, while the mean age for the Romanian group was 36.03, a difference of 6.717. On average the Romanian



children were diagnosed six months earlier than the Irish children. Thus, the age of children when diagnosed with ASD and the duration of the diagnosis process (parents' first appointment for assessment until completed) in Ireland were different than the age of children when diagnosed with ASD and the duration of diagnosis process in Romania.

Whatever the reasons for the delays in the diagnostic process, it is clear that delays in obtaining an ASD diagnosis contribute to negative experience in accessing services and can cause parental distress. These delays may affect children's participation in early intervention services (Goin and Myers, 2004). Thus, improvements in the diagnostic process are necessary.

Studies found that higher levels of parental education and income were associated with earlier diagnosis and greater satisfaction by parents with the diagnostic process. Generally, parents were more satisfied with the diagnostic process when they saw fewer professionals in order to obtain the diagnosis and when the children received the diagnoses at younger ages (Goin-Kochel et al., 2006).

Mansell and Morris (2004), conducted a study in the UK and found that early diagnosis and prompt diagnosis were the key factors that contributed to reducing parental stress.

The duration of the diagnosis process and parents' experience in accessing services are interconnected. The results of the present study indicate that the duration of the diagnosis process was associated with positive or negative experience. In the Irish group, the average duration of diagnosis was 14.92 months. As a result, parents' experience was negative in accessing services for their child (assessment, therapies and educational services). In the Romanian group, the average duration of diagnosis was 4.63 months, which indicated a positive experience in accessing services (assessment, therapies, educational services) (see Table 10-1, Table 10-2).

In conclusion, a longer duration of diagnosis resulted in a negative experience in accessing services and a shorter duration of diagnosis resulted in positive experience in accessing services.

Table 10-1. Experience of services and duration of diagnosis (Ireland).

Subject ID	Experience of services (assessment and therapies)	Experience of educational services	Duration of diagnosis (months)
1	Negative	negative	24
2	Negative	negative	6
3	Negative	negative	13
4	Negative	negative	9
5	Negative	negative	11
6	Negative	negative	18
7	Negative	negative	7
8	Negative	negative	17
9	Negative	negative	12
10	Negative	negative	7
11	Negative	negative	30
12	Negative	negative	20
13	Negative	negative	9
14	Negative	negative	24
15	Negative	positive	12
16	Negative	negative	18
17	Negative	negative	6
18	Negative	positive	12
19	Negative	negative	12
20	Negative	negative	24
21	Negative	negative	9
22	Negative	negative	12
23	Negative	negative	22
24	Negative	negative	24

Table 10-2. Experience of services and duration of diagnosis (Romania).

Subject ID	Experience of services (assessment and therapies)	Experience of educational services	Duration of diagnosis (months)
1	Positive	positive	1
2	Positive	positive	4
3	Negative	negative	1
4	Positive	positive	12
5	Positive	positive	6
6	Positive	negative	1
7	Positive	positive	3

8	Positive	positive	8
9	Positive	positive	1
10	Positive	positive	3
11	Positive	positive	1
12	Positive	positive	1
13	Positive	positive	24
14	Positive	positive	4
15	Positive	positive	1
16	Positive	positive	1
17	Positive	positive	1
18	Positive	positive	1
19	Positive	positive	1
20	Positive	positive	6
21	Positive	negative	12
22	Positive	positive	1
23	Positive	positive	1
24	negative	negative	8
25	Positive	positive	1
26	negative	positive	12
27	Positive	positive	6
28	Positive	positive	6
29	Positive	positive	10
30	Positive	positive	1

## 11. Limitations and further research

The present study has several limitations. Families are complex systems and it is very difficult to find and design assessment methods that can include significant information about families. For this research, both FACES IV and semi-structured interview were used to explore and explain family experience of ASD diagnostic process.

The results presented in this research study indicate that both instruments used were able to bring valuable information about family functioning during the diagnostic process. However, it is important to consider that the diagnostic process of children with ASD is complex and involves many variables. These variables include a holistic approach to diagnosis and involvement of legislative, health, education, social sectors. Above all, family needs should be take into account with regard to their child's diagnosis.

The main limitation of this study was the difficulty in the recruitment of Irish families and this may bias the representation of family's experience during the diagnostic process of their child in Ireland. However, the statistical representation is satisfactory to validate this research.

As only two countries were involved in this research, the results may not be generalized. As Daley (2002) suggests, there is a need for cross-cultural research on the pervasive developmental disorders.

Research on the pervasive developmental disorders within a cultural context and in developing countries has received limited attention from both the fields of mental health and anthropology.

(Daley, 2002, p. 531)

Another limitation is the geographical area selected for this research, which may not include the general perception of family experience during the diagnostic process of their child. Little is known about the diagnostic process and its implications in other geographic areas in Ireland and Romania.

Dublin and Timisoara are two developed cities, and services for children with ASD could be different, possibly more developed than in another parts of the country. Therefore, the sample was limited to parents who lived in the same geographic area and may offer a representation of a limited sector of local experiences. However, in the present study, the semi-structured interview included parents' general perception and knowledge about children with ASD in their own country and in the other country (Romania versus Ireland).

The present study did not offer similarities and differences to other regions in Ireland and Romania; more research on other areas in both countries would be necessary to confirm the conclusions of this thesis.

As previously mentioned and described in Chapter 1.4, ASD seems to vary in different cultures. The present study confirms that there are differences and some similarities in how parents face the diagnosis of ASD of their child in two different cultures (Ireland and Romania). For more understanding of ASD, further research can use the same instruments in different cultures to measure parents' experience and family functioning during the diagnostic process of their child.

Of course, ultimately, it would be important to study aspects of family functioning during the diagnosis stage across Europe, and further afield, in the United States of America, Asia, Africa and Australia. A global study could provide useful information for both parents and professionals involved in the autism field. Further research is predominantly needed for examining parents' experience during the diagnosis process of their child.

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## 13. Annexes

### Appendix 1

#### PARTICIPANT INFORMATION and CONSENT FORM

##### Facing the diagnosis of autism spectrum disorder in Europe: How do families cope in Ireland and Romania

*You are being invited to take part in a study that is conducted as part of my PhD, supervised by Dr Karola Dillenburger, Queen's University of Belfast. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.*

*Thank you for reading this.*

*In this study, we want to learn more about families of children with autism spectrum disorder and how they are functioning during the diagnosis process, so we can develop better support systems and help.*

*We will compare families living in Ireland with families living in Romania and that's why you were chosen to take part. We expect that there will be 1 or 2 meetings shortly after you have received the diagnosis for your child.*

*The participation in this study is entirely voluntary. All information about you will be kept strictly confidential and have your name removed so that you cannot be recognized from it. The results of the study will be used for research and training purposes only.*

*The Research Ethics Committee, Queen's University Belfast as well as the ethics committees of Cherry Orchard Hospital (Ireland) and Association Casa Faenza, Community Centre for Autistic Children (Romania) have approved this research.*

*It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent*

*form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the service you receive.*

Cornelia Munteanu  
Queen's University Belfast  
School of Education  
69/71 University Street  
Belfast BT7 1HL  
e-mail: [cmunteanu01@qub.ac.uk](mailto:cmunteanu01@qub.ac.uk)

*Each participant will receive a copy of the Information sheet and a signed consent form.*

*Thank you*

## Appendix 2

### CONSENT FORM

Title of Project:

Facing the diagnosis of autism spectrum disorder in Europe: How do families cope in  
Ireland and Romania

Name of Researcher:

Cornelia Munteanu, *School of Education, Queen's University of Belfast*

Please initial box

1.I confirm that I have read and understand the information sheet ☐  
for the above study and have had the opportunity to ask questions.

2.I understand that my participation is voluntary and that I am free ☐  
to withdraw at any time, without giving any reason,  
without services or legal rights being affected.

3.I agree to take part in the above study. ☐

\_\_\_\_\_  
\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
\_\_\_\_\_  
Date

\_\_\_\_\_  
\_\_\_\_\_  
Signature

\_\_\_\_\_  
\_\_\_\_\_  
Researcher

\_\_\_\_\_  
\_\_\_\_\_  
Date

\_\_\_\_\_  
\_\_\_\_\_  
Signature

1 for participant; 1 for researcher



## Appendix 3

### INTERVIEW SCHEDULE

Facing the diagnosis of autism spectrum disorder in Europe: How do families cope in  
Ireland and Romania

a) Ireland b) Romania

b)

Personal information:

Child's name (initials):

Diagnostic:

Gender: M F

Age:

Participants:

Family composition (gender, age, marital status, education, employment):

	Gender	Age	Marital status	Education	Impairment	Employment
Mother						
Father						
Other?..						
Child						
Child						
....						

1. Age of child when received the AD diagnosis:
2. How long was the diagnosis process from start until diagnosis was completed?
3. What changes in family life did you experience since you received the diagnosis?
4. Describe your feelings regarding your child's diagnostic of autism.

5. Who did you discuss your child's diagnosis with (e.g. family members, extended family, friends, professionals etc)?
6. What were your first thoughts when you were being informed about your child's diagnosis?
7. Did you discuss with other parents who have children diagnosed with autism and if so, did you find this helpful?
8. What were your main worries when receiving the diagnosis?
9. What type of services/treatment for children with autism are you aware of?
10. Describe your experience accessing services where you live.
11. What is your experience regarding accessing educational services for your child?
12. What would be the role of mother in raising a child with autism?
13. What would be the role of father in raising a child with autism?
14. Describe a regular day with your child and family.
15. Describe the experience of siblings, grandparents dealing with the diagnosis of autism.
16. How has the diagnosis affected relationships within the family?
  - A) between parents
  - B) between brothers and sisters
  - C) between nuclear family and other family members, e.g. grandparents, aunts/uncles, cousins etc
17. What do you know about children diagnosed with autism in Romania?

- 18.** What do you know about children diagnosed with autism in Ireland?
- 19.** How do you think the diagnosis process could be improved where you live?
- 20.** Do you have any questions?

## Appendix 4

### *Informarea participantilor*

&

### *Foaia de consimtamant*

#### *Diagnosticul autismului in Europa: Cum se confrunta cu diagnosticul familiile din Irlanda si Romania*

Sunteti invitat sa luati parte in acest studiu care face parte din teza mea de doctorat coordonata de Dr. Karola Dillenburger, Queen's University Belfast. Inainte de a decide sa participati este important sa intelegeti scopul acestei cercetari si implicatiile acesteia. Va rog sa cititi cu atentie informatia si sa va consultati cu altcineva daca doriti. Intrebati orice va este neclar si daca doriti mai multa informatie. Decideti daca doriti sau nu doriti sa participati in aceasta cercetare.

Va multumesc pentru timpul acordat!

In acest studiu dorim sa cunoastem mai multe despre familiile copiilor cu autism si cum functioneaza ele de-a lungul procesului de diagnostic pentru a putea dezvolta o retea mai buna de suport. Vom compara familii din Romania cu familii din Irlanda iar acesta este motivul pentru care v-am ales sa participati. Participarea consta intr-o intalnire cu cercetatorul in perioada de dupa primirea diagnosticului.

Participarea dumneavoastra in acest studiu este in totalitate voluntara. Toata informatia va fi strict confidentiala si va avea numele dumneavoastra sters pentru a nu putea fi identificat. Rezultatele studiului vor fi folosite doar in scopul acestei cercetari.

Comitetul Etic de la Queen's University Belfast, Comitetul Etic al Spitalului "Cherry Orchard" din Dublin Irlanda precum si Comitetul Etic al Asociatiei Casei Faenza, Centrul Comunitar pentru Copii cu Autism din Timisoara au aprobat aceasta cercetare.

Depinde de dumneavoastra daca doriti sa participati sau nu in aceasta cercetare. Daca decideti sa participati o sa primiti informatie despre aceasta cercetare si o sa fiti rugati sa semnati acordul de participare. Daca decideti sa va retrageti din cercetare puteti sa o faceti oricand fara sa dati un motiv. Decizia de retragere sau decizia de nu participa nu va afecta serviciile actuale pe care le primiti.

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tel: 00353863283181

Fiecare participant va primi o copie a foii informative precum si foaia de  
consimtamant semnata.

*Va multumesc!*

## Appendix 5

### Foaia de Consimtamant

Titlul lucrării:

*Diagnosticul autismului in Europa: Cum se confrunta cu diagnosticul familiile din Irlanda si Romania*

Numele Cercetatorului:

Cornelia Munteanu, *School of Education, Queen's University of Belfast*

Va rog bifati

1. Confirm ca am citit si inteles foaia informativa a acestui studiu si am avut oportunitatea sa pun intrebari ☐

2. Inteleg ca participarea mea este voluntara si ca sunt liber sa ma retrag oricand fara a da un motiv sau fara ca serviciile pe care le primesc si drepturile legale sa imi fie afectate ☐

3. Sunt de acord sa particip in acest studiu ☐

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Numele Participantului

Data

Semnatura

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Cercetator

Data

Semnatura

1 pentru participant; 1 pentru cercetator

## Appendix 6

### *Family Adaptability and Cohesion Evaluation Scale IV (FACES IV)*

#### **FACES IV: Background Information**

**Subject ID** \_\_\_\_\_ **Age:** \_\_\_\_ **Sex:** M: \_\_\_\_ F: \_\_\_\_ **Date:** \_\_\_\_\_

**Education:**

- (a) \_\_\_\_ Some High School      (b) \_\_\_\_ Completed High School  
(c) \_\_\_\_ Some college      (d) \_\_\_\_ Completed College      (e) \_\_\_\_ Advanced Degree

**Income: (If relevant)**

- (a) \_\_\_\_ Less than \$10,000      (b) \_\_\_\_ \$10-20,999      (c) \_\_\_\_ \$21-30,999  
(d) \_\_\_\_ \$31-40,999      (e) \_\_\_\_ \$41-50,999      (f) \_\_\_\_ \$51-60,999  
(g) \_\_\_\_ \$61-80,999      (h) \_\_\_\_ \$81-99,999      (i) \_\_\_\_ \$100,000 or more

**Ethnic Background: (check all that apply)**

- (a) \_\_\_\_ Asian American      (d) \_\_\_\_ Hispanic/Latino      (g) \_\_\_\_ White/Caucasian  
(b) \_\_\_\_ Black/African American      (e) \_\_\_\_ Mixed Race  
(c) \_\_\_\_ Hawaiian or Pac. Islander      (f) \_\_\_\_ Native American

**Current relationship status:**

- (a) \_\_\_\_ Single, never married      (e) \_\_\_\_ Married, not first marriage  
(b) \_\_\_\_ Single, divorced      (f) \_\_\_\_ Life-partnership  
(c) \_\_\_\_ Single, widowed      (g) \_\_\_\_ Living together  
(d) \_\_\_\_ Married, first marriage      (h) \_\_\_\_ Separated

**Current living arrangement:**

- (a) \_\_\_\_ Alone      (d) \_\_\_\_ With Others  
(b) \_\_\_\_ With Parents      (e) \_\_\_\_ With Children  
(c) \_\_\_\_ With Partner      (f) \_\_\_\_ With Partner and Children

**Use Current Family: If no current Family, use Family of Origin**

**Family Structure:** (a) \_\_\_\_ Two parents (biological)      (d) \_\_\_\_ Two Parent (same sex)  
(b) \_\_\_\_ Two parents (step family)      (e) \_\_\_\_ One Parent  
(c) \_\_\_\_ Two parents (adoptive)

**Family Member:** (a) \_\_\_\_ Father      (c) \_\_\_\_ First Child      (e) \_\_\_\_ Third Child  
(b) \_\_\_\_ Mother      (d) \_\_\_\_ Second Child      (f) \_\_\_\_ Fourth or Younger Child

**Number of Children in Family:** (a) \_\_\_\_ None      (b) \_\_\_\_ One      (c) \_\_\_\_ Two      (d) \_\_\_\_ Three  
(e) \_\_\_\_ Four      (f) \_\_\_\_ Five      (g) \_\_\_\_ Six or more

## FACES IV: Questionnaire

### Directions to Family Members:

1. All family members over the age 12 can complete FACES IV.
2. Family members should complete the instrument independently, not consulting or discussing their responses until they have been completed.
3. Fill in the corresponding number in the space on the provided answer sheet.

1	2	3	4	5
Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

1. Family members are involved in each others lives.
2. Our family tries new ways of dealing with problems.
3. We get along better with people outside our family than inside.
4. We spend too much time together.
5. There are strict consequences for breaking the rules in our family.
6. We never seem to get organized in our family.
7. Family members feel very close to each other.
8. Parents equally share leadership in our family.
9. Family members seem to avoid contact with each other when at home.
10. Family members feel pressured to spend most free time together.
11. There are clear consequences when a family member does something wrong.
12. It is hard to know who the leader is in our family.
13. Family members are supportive of each other during difficult times.
14. Discipline is fair in our family.
15. Family members know very little about the friends of other family members.
16. Family members are too dependent on each other.
17. Our family has a rule for almost every possible situation.
18. Things do not get done in our family.
19. Family members consult other family members on important decisions.
20. My family is able to adjust to change when necessary.
21. Family members are on their own when there is a problem to be solved.
22. Family members have little need for friends outside the family.
23. Our family is highly organized.
24. It is unclear who is responsible for things (chores, activities) in our family.
25. Family members like to spend some of their free time with each other.
26. We shift household responsibilities from person to person.
27. Our family seldom does things together.
28. We feel too connected to each other.
29. Our family becomes frustrated when there is a change in our plans or routines.
30. There is no leadership in our family.



1	2	3	4	5
Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

31. Although family members have individual interests, they still participant in family activities.
32. We have clear rules and roles in our family.
33. Family members seldom depend on each other.
34. We resent family members doing things outside the family.
35. It is important to follow the rules in our family.
36. Our family has a hard time keeping track of who does various household tasks.
37. Our family has a good balance of separateness and closeness.
38. When problems arise, we compromise.
39. Family members mainly operate independently.
40. Family members feel guilty if they want to spend time away from the family.
41. Once a decision is made, it is very difficult to modify that decision.
42. Our family feels hectic and disorganized.

- 
43. Family members are satisfied with how they communicate with each other.
  44. Family members are very good listeners.
  45. Family members express affection to each other.
  46. Family members are able to ask each other for what they want.
  47. Family members can calmly discuss problems with each other.
  48. Family members discuss their ideas and beliefs with each other.
  49. When family members ask questions of each other, they get honest answers.
  50. Family members try to understand each other's feelings
  51. When angry, family members seldom say negative things about each other.
  52. Family members express their true feelings to each other.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

How satisfied are you with:

53. The degree of closeness between family members.
54. Your family's ability to cope with stress.
55. Your family's ability to be flexible.
56. Your family's ability to share positive experiences.
57. The quality of communication between family members.
58. Your family's ability to resolve conflicts.
59. The amount of time you spend together as a family.
60. The way problems are discussed.
61. The fairness of criticism in your family.
62. Family members concern for each other.

*Thank you for Your Cooperation!*

## Appendix 7

### Scala pentru Adaptabilitatea si Coeziunea familiei IV (FACES IV)

#### FACES IV CHESTIONAR SI FOI DE RASPUNS

David H. Olson Ph.D.

Dean M. Gorall Ph.D.

Judy W. Tiesel Ph.D.

2006

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Version 3/07

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#### FACES IV: INFORMATII GENERALE

ID subiect (4 cifre) \_\_\_\_\_ Varsta: \_\_\_\_\_ Sex: M: \_\_\_\_ F: \_\_\_\_ Data: \_\_\_\_\_

Educatie:

- (a) \_\_\_\_ catva liceu (b) \_\_\_\_ absolvent de liceu  
(c) \_\_\_\_ ceva studii superioare (d) \_\_\_\_ absolvent de studii superioare  
(e) \_\_\_\_ studii avansate

Venitul: (daca e relevant)

- (a) \_\_\_\_ mai putin de \$10,000 (b) \_\_\_\_ \$10-20,000 (c) \_\_\_\_ \$20-30,000  
(d) \_\_\_\_ \$30-40,000 (e) \_\_\_\_ \$40-50,000 (f) \_\_\_\_ \$50-60,000  
(g) \_\_\_\_ \$60-80,000 (h) \_\_\_\_ \$80-100,000 (i) \_\_\_\_ \$100,000 sau mai  
mult

Etnia:

- (a) \_\_\_\_ Asiatic American (d) \_\_\_\_ Hispanic/Latino (g) \_\_\_\_  
Alb/Caucasian  
(b) \_\_\_\_ Negru/African American (e) \_\_\_\_ Rasa mixta  
(c) \_\_\_\_ Hawaiian or Pac. Islander (f) \_\_\_\_ Nativ American

Statusul current al relatiei:

- (a) \_\_\_\_ Singur(a), necasatorit(a) (e) \_\_\_\_ Casatorit(a), nu prima  
casatorie  
(b) \_\_\_\_ Singur(a), divortat(a) (f) \_\_\_\_ Parteneriat pe viata  
(c) \_\_\_\_ Singur(a), vaduv(a) (g) \_\_\_\_ Concubinaj  
(d) \_\_\_\_ Casatorit(a), Prima casatorie (h) \_\_\_\_ Separati

Aranjamentele actuale de locuit:

- (a) \_\_\_\_ Singur(a) (e) \_\_\_\_ Cu altii  
(b) \_\_\_\_ Cu parintii (f) \_\_\_\_ Cu copii  
(c) \_\_\_\_ Cu partenerul (g) \_\_\_\_ Cu partenerul si copiii

Folositi Familia actuala: Daca nu folositi familia actuala, folositi familia de origine:

Structura familiei: (a) \_\_\_ 2 parinti (biologici) (d) \_\_\_ 2 parinti (acelasi sex)  
(b) \_\_\_ 2 parinti (fam vitrega) (e) \_\_\_ un parinte  
(c) \_\_\_ 2 parinti (adoptivi)

Membrii familiei:

(a) \_\_\_ tata (c) \_\_\_ primul copil (e) \_\_\_ al 3 lea copil  
(b) \_\_\_ mama (d) \_\_\_ al II lea copil (f) \_\_\_ al 4 lea copil sau cel mai mic

Numarul copiilor in familie:

(a) \_\_\_ nici unul (b) \_\_\_ unu (c) \_\_\_ doi (d) \_\_\_ trei  
(e) \_\_\_ patru (f) \_\_\_ cinci (g) \_\_\_ sase sau mai multi

#### CHESTIONARUL FACES IV

Instructiuni pentru membri familiei:

1. Toti membri familiei peste 12 ani pot sa completeze FACES IV.
2. Membri familiei trebuie sa completeze formularul independent, fara sa se consulte sau sa discute raspunsurile decat dupa ce au terminat.
3. Completati numarul care se potriveste situatiei dvs in foaia de raspuns alaturata.

1	2	3	4	5
Total dezacord	Dezacord	Nehotarat	De acord	Total de acord

1. Membri familei sunt implicati in viata celuilat.
2. Familia noastra incearca noi modalitati de a face fata problemelor.
3. Ne intelegem mai bine cu cei din afara familiei decat cu cei din interiorul familiei.
4. Petrecem prea mult timp impreuna.
5. Sunt consecinte stricte pentru incalcarea regulilor in familia noastra.
6. Niciodata nu parem a ne putea organiza in familie.

7. Membri familiei se simt foarte apropiati unii de altii.
8. Parintii impart in mod egal conducerea in familie.
9. Membri familiei par a evita contactul intre ei cand sunt acasa.
10. Membri familiei se simt presati sa petreaca majoritatea timpului liber impreuna.
11. Exista consecinte clare cand un membru al familiei face ceva gresit.
12. Este greu de stiut cine e liderul in familia noastra.
13. Membri familiei se sprijina unii pe altii de-a lungul perioadelor dificile.
14. Disciplina e corecta in familia noastra.
15. Membri familiei stiu foarte putine despre prietenii altor membri din familie.
16. Membri familiei sunt prea dependenti unii de altii.
17. Familia noastra are cate o regula pentru aproape fiecare situatie posibila.
18. In familia noastra lucrurile nu ajung sa se finalizeze.
19. Membri familiei se consulta cu altii membri ai familiei asupra deciziilor importante.
20. Familia mea e capabila sa se adapteze schimbarilor cand este necesar.
21. Membri familiei sunt pe cont propriu cand apare o problema de rezolvat.
22. Membri familiei au o nevoie scazuta de prieteni din afara familiei.
23. Familia noastra e foarte organizata.
24. Este neclar cine e responsabil pentru anumite activitati in familia noastra.
25. Membrilor familiei le place sa petreaca parte din timpul lor liber impreuna.
26. Responsabilitatile casei le transferam de la o persoana la alta.
27. Familia noastra foarte rar face lucruri impreuna.
28. Ne simtim prea legati unii de altii
29. Familia noastra devine frustrate cand intervine o schimbare in planurile sau rutinele noastre.
30. Nu exista nici un leadership (conducere) in familia noastra.

1	2	3	4	5
Total dezacord	Dezacord	Nehotarat	De acord	Total de acord

31. Chiar daca membri familiei au interese individuale, ei tot participa la activitatile familiei.
32. Avem reguli si roluri clare in familia noastra.
33. Membri familiei depind foarte rar unii de altii.
34. Ne displac membri familiei care fac lucruri in afara familiei.
35. Este important sa respectam regulile in familia noastra.
36. Familiei noastre ii este greu sa tina seama cine indeplineste diferite sarcini in casa.
37. Familia noastra are un echilibru bun intre separare si apropiere.
38. Cand se ivesc problemele, facem compromisuri.
39. Membri familiei actioneaza in mare parte singuri.
40. Membri familiei se simt vinovati daca vor sa petreaca timp departe de familie.
41. Odata ce se ia o decizie, este foarte greu sa mai fie schimbata.
42. Familia noastra se simte haotica si dezorganizata.
- 
43. Membri familiei sunt satisfacuti de modul in care comunica unii cu altii.
44. Membri familiei stiu sa se asculte unii pe altii.
45. Membri familiei isi exprima afectiunea unii fata de altii.
46. Membri familiei sunt capabili sa ceara unii de la altii ceea ce vor.
47. Membri familiei pot discuta calm problemele unii cu altii.
48. Membri familiei discuta ideile si convingerile unii cu altii.
49. Cand membri familiei pun intrebari, primesc raspunsuri sincere.
50. Membri familiei incearca sa inteleaga ce simte celalalt.
51. La furie, membri familiei rar spun lucruri negative unul despre celalalt.
52. Membri familiei isi exprima adevaratele emotii fata de ceilalti.

1	2	3	4	5
Foarte nesatisfacut	Oarecum nesatisfacut	Satisfacut	Foarte satisfacut	Extrem de satisfacut

Cat de satisfacut sunteti in legatura cu:

53. Gradul de apropiere dintre membri familiei.
54. Abilitatea familiei dvs. de a face fata stresului.
55. Abilitatea familiei dvs. de a fi flexibila.
56. Abilitatea familiei de a impartasi experiente positive.
57. Calitatea comunicarii dintre membri familie.
58. Abilitatea familiei de a rezolva conflictele.
59. Timpul petrecut impreuna ca familie.
60. Felul in care sunt discutate problemele
61. Corectitudinea critismului in familie.
62. Inrijorarea membrilor familiei unii fata de ceilalti

*MULTUMIM DE COLABORARE!*

#### FACES IV – FOAIE DE RASPUNS

ID subiect(4 cifre)\_\_\_\_\_ Varsta: \_\_\_\_\_ Sex: M: \_\_\_\_ F: \_\_\_\_ Data: \_\_\_\_\_

1	2	3	4	5
Total dezacord	Dezacord	Nehotarat	De acord	Total de acord

- |         |          |          |          |          |          |          |
|---------|----------|----------|----------|----------|----------|----------|
| 1. ____ | 7. ____  | 13. ____ | 19. ____ | 25. ____ | 31. ____ | 37. ____ |
| A. ____ |          |          |          |          |          |          |
| 2. ____ | 8. ____  | 14. ____ | 20. ____ | 26. ____ | 32. ____ | 38. ____ |
| B. ____ |          |          |          |          |          |          |
| 3. ____ | 9. ____  | 15. ____ | 21. ____ | 27. ____ | 33. ____ | 39. ____ |
| C. ____ |          |          |          |          |          |          |
| 4. ____ | 10. ____ | 16. ____ | 22. ____ | 28. ____ | 34. ____ | 40. ____ |
| D. ____ |          |          |          |          |          |          |
| 5. ____ | 11. ____ | 17. ____ | 23. ____ | 29. ____ | 35. ____ | 41. ____ |
| E. ____ |          |          |          |          |          |          |

6. \_\_\_\_ 12. \_\_\_\_ 18. \_\_\_\_ 24. \_\_\_\_ 30. \_\_\_\_ 36. \_\_\_\_ 42. \_\_\_\_  
 F. \_\_\_\_

1	2	3	4	5
Total dezacord	Dezacord	Nehotarat	De acord	Total de acord

43. \_\_\_\_ 44. \_\_\_\_ 45. \_\_\_\_ 46. \_\_\_\_ 47. \_\_\_\_ 48. \_\_\_\_  
 \_\_\_\_

49. \_\_\_\_ 50. \_\_\_\_ 51. \_\_\_\_ 52. \_\_\_\_ SUMA \_\_\_\_ =  
 \_\_\_\_%

1	2	3	4	5
Foarte nesatisfacut	Oarecum nesatisfacut	Satisfacut	Foarte satisfacut	Extrem de satisfacut

53. \_\_\_\_ 54. \_\_\_\_ 55. \_\_\_\_ 56. \_\_\_\_ 57. \_\_\_\_ 58. \_\_\_\_  
 \_\_\_\_

59. \_\_\_\_ 60. \_\_\_\_ 61. \_\_\_\_ 62. \_\_\_\_ SUMA \_\_\_\_  
 = \_\_\_\_%

*MULTUMIM PENTRU COLABORARE!*



## Appendix 8

### GHID DE INTERVIU

#### *Diagnosticul autismului in Europa: Cum se confrunta cu diagnosticul familiile din Irlanda si Romania*

c) Irlanda b) Romania

d)

Informatii Personale:

Numele copilului (initialele):

Diagnostic:

Sex: M F

Varsta:

Participanti:

Compozitia familiei (sex, varsta, statutul marital, starea de sanatate, educatie, loc de munca):

	Sex	Varsta	Statut marital	Educatie	Starea de sanatate	Loc de munca
Mama						
Tata						
Altii?..						
Copil						
Copil						
....						

1. Varsta copilului cand a primit diagnosticul de autism:
2. Cat a durat procesul de diagnostic de la inceput pana cand a fost primit?
3. Ce schimbari ati experimentat in viata de familie de cand ati primit diagnosticul?
4. Descrieti sentimentele dumneavoastra in legatura cu diagnosticul copilului dumneavoastra.

5. Cu cine ati discutat diagnosticul copilului dumneavoastra (de exemplu, membrii familiei, familia extinsa, prieteni, profesionisti etc)?
6. Care au fost primele ganduri cand ati fost informat ca copilul dumneavoastra are autism?
7. Ati discutat cu alti parinti care au copii cu autism? Daca da, a fost folositor?
8. Care au fost ingrijorarile principale cand ati primit diagnosticul?
9. Ce tipuri de servicii si terapii stiti despre copiii cu autism?
10. Descrieti experienta dumneavoastra in legatura cu accesarea serviciilor pentru copii cu autism in aceasta zona.
11. Care este experienta dumneavoastra in legatura cu serviciile educationale disponibile pentru copilul dumneavoastra?
12. Care credeti ca este rolul mamei in cresterea unui copil cu autism?
13. Care credeti ca este rolul tatalui in cresterea unui copil cu autism?
14. Descrieti o zi obisnuita cu copilul dumneavoastra.
15. Descrieti experienta fratilor, bunicilor in legatura cu diagnosticul.
16. Cum a afectat diagnosticul relatiile de familie?
  - D) Dintre parinti
  - E) Dintre frati/surori
  - F) Dintre familia nucleara si alti membrii de familie: bunici, verisori, unchi/matusi etc
17. Ce stiti despre copiii cu autism din Romania?

**18.** Ce stiti despre copiii cu autism din Irlanda?

**19.** Cum credeti ca ar putea fi imbunatatit procesul de diagnostic in aceasta zona?

**20.** Aveti intrebari?

#### 14. List of abbreviations

- ABA Applied Behaviour Analysis
- ADD Attention Deficit Disorder
- ADHD Attention Deficit and Hyperactivity Disorder
- ADI-R Autism Diagnostic Interview–Revised
- ADOS-G Autism Diagnostic Observations Scale-Generic
- AQ Autism-spectrum Quotient
- ASD Autism Spectrum Disorder
- ASQ Autism Screening Questionnaire
- CAMHS Child and Adolescent Mental Health Services
- CARS Childhood Autism Rating Scale
- CARS2-HF Childhood Autism Rating Scale 2 - High-Functioning Version Rating Booklet
- CARS2-QPC Childhood Autism Rating Scale 2 - Questionnaire for Parents or Caregivers
- CARS2-ST Childhood Autism Rating Scale 2 - Standard Version Rating Booklet
- CHAT Checklist for Autism in Toddlers
- DISCO Diagnostic Interview for Social and Communication Disorders
- DSM-I Diagnostic and Statistical Manual – First Edition
- DSM-II Diagnostic and Statistical Manual – Second Edition
- DSM-III Diagnostic and Statistical Manual – Third Edition
- DSM-IV Diagnostic and Statistical Manual – Fourth Edition
- DSM-V Diagnostic and Statistical Manual – Fifth Edition
- EAPHA European Autism Public Health Alliance
- EEG Electroencephalogram
- EIT Early Intervention Team
- EPSN Education for Persons with Special Educational Needs
- EU European Union
- FACES IV Family Adaptability and Cohesion Evaluation Scale IV
- GARS Gilliam Autism Rating Scale
- HSE Health Service Executive

- ICD-10 International Classification of Diseases.
- ID Intellectual Disability
- IQ Intelligence Quotient
- LHO Local Health Office
- NAS National Autistic Society
- NEPS National Education Psychological Service
- NHST Null Hypothesis Significance Testing
- PDD Pervasive Developmental Disorders
- PDD-NOS Pervasive Developmental Disorder-Not Otherwise Specified
- PECS Picture Exchange Communication System
- PEP-R Psychoeducational Profile Revised
- PHN Public Health Nurse
- PRSI Pay Related Social Insurance
- PSI Psychological Society of Ireland
- SCQ Social Communication Questionnaire
- SESS Special Education Support Service
- SLI Speech and Language Impairment
- SOC Sense Of Coherence
- SPSS Statistical Package for the Social Science
- SRS Social Responsiveness Scale
- TEACCH Treatment and Education of Autistic and Related Communication Handicapped Children
- VABS Vineland Adaptive Behavior Scales
- WPPSI-R Wechsler Preschool and Primary Scale of Intelligence Rev. ed.